


Determining and Comparing the Activity Requirements and Participation Experiences of Xhosa Women with Stroke in Relation to Life Roles in Rural and Urban Environments

by
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The crest of Stellenbosch University is centered behind the text. It features a shield with various symbols, including a book and a torch, surrounded by a wreath. Below the shield is a banner with the Latin motto "Festina coluunt cultus recti".

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March 2017

Declaration

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Abstract

Introduction

Stroke impacts on a person's body function, performance in meaningful activities and participation in life roles. The complex health transition in South Africa has seen a rise in the incidences of stroke in a younger population.

Objectives

The aim of this study is to describe and compare the activity requirements and personal experiences of Xhosa women with stroke in relation to performance of their life roles in rural and urban settings.

Methods

This descriptive, cross-sectional study uses a convergent mixed method design. Quantitative and qualitative data was obtained from 11 participants in the rural setting of the Eastern Cape and 9 participants in the Western Cape of South Africa.

The quantitative data was obtained using the Barthel Index, EuroQol five-dimension questionnaire (EQ-5D). A self-developed questionnaire was used to gather information on participants' demographic and environmental information. The qualitative data was obtained by doing individual semi-structured interviews.

The quantitative data was analysed using summative and descriptive statistics in MS Excel and STATA 14 software. The qualitative data was analysed using deductive and inductive analysis in Atlas.ti version 7 software. Complementary data from different data sources were triangulated.

Results

The median age for the rural participants was 42 years (28-72) and 56 years (31-65) for urban participants. In the rural setting, most participants reported that they relied on natural water sources and has poor access to sanitation services.

The total median BI score was 80 for rural (40-95) and urban (10-100) participants. The median scores for rural participants were higher in bathing and mobility, while urban participants score higher in feeding and transfers.

The median EQ-5D VAS score was 50 (30-80) in rural and 55 (20-90) in urban participants. The rural participants reported less problems associated with HRQoL state dimensions for self-care and, anxiety and dimension.

The deductive analysis of the qualitative data described the life roles of Xhosa women as self-care role, being a provider, caregiver and community members. These role responsibilities and how environmental factors shaped activities and task requirements were described and compared between both setting.

The inductive findings of the qualitative data described the personal experiences of Xhosa women with stroke within three emerging themes namely: theme 1 – “I struggle with nothing, they do so much for me”, theme 2 – “I still like looking smart” and theme 3 – “Dead, but alive”. These themes associated with participants’ perception of family support and their drive to strategize in order to participate in life roles.

Conclusion

This study found that life roles for women with stroke in rural and urban settings were similar. However, the activity requirements of role responsibilities were shaped by the environmental factors in rural and urban setting, leading to additional task requirements to overcome barriers. Participants’ participation experiences were similar in rural and urban settings as perception of their social support contributed to their perceived HRQoL. The overlapping of data sources in this study highlighted the limitation of the BI in addressing the contextual factors influencing activities of daily living and comparing scores between populations in different settings or cultures.

KEYWORDS: STROKE, ACTIVITY, PARTICIPATION, ROLES, XHOSA, WOMEN, ENVIRONMENT, EXPERIENCES, RURAL, URBAN

Opsomming

Inleiding

Beroerte affekteer en beperk 'n persoon se liggaamsfunksies, die uitvoering van betekenisvolle aktiwiteite en vervulling van lewensrolle. In die gekompliseerde gesondheidsverandering in Suid Afrika is daar 'n beduidende voorkoms van beroerte onder die jonger geslag.

Doel van die Studie

Die doel van die studie is om die aktiwiteitsvereistes, lewensrolle en persoonlike ervarings van Xhosa vroue met beroerte in stedelike en landelike omgewings te vergelyk en te beskryf.

Metodologie

Die beskrywende dwarsnitstudie gebruik 'n konkurrente gemengde metode. Kwantitatiewe en kwalitatiewe inligting is van 11 deelnemers in die landelike omgewing in die Oos-Kaap en 9 deelnemers in die Wes-Kaap provinsies van Suid- Afrika ingesamel.

Die kwantitatiewe inligting is met die Barthel Indeks, EuroQol vyf-demensie vraelys (EQ-5D) ingesamel. 'n Vraelys is opgestel om inligting van deelnemers se demografie en omgewing in te samel. 'n Gedeeltelike gestruktureerde vraelys en onderhoude is gebruik om kwalitatiewe inligting te verkry.

Die kwantitatiewe inligting is deur die gebruik van opsommende en beskrywende statistieke ontleed. Die kwalitatiewe inligting is deur die gebruik van deduktiewe en induktiewe ontledings verwerk. Inligting van verskillende bronne is getrianguleer.

Resultate

Die mediaan ouderdom van landelike deelnemers was 42 jaar (40-95) en deelnemers in die stedelike gebied was 56 jaar (31-65). Die meeste deelnemers in die landelike gebied het terugvoering gegee dat hulle afhanklik is van natuurlike waterbronne en swak sanitasie dienste ondervind.

Die totale mediaan BI telling vir die landelike (40-95) en stedelike (10-100) deelnemers was 80. Die mediaan telling vir bad en mobiliteit van landelike deelnemers was hoër terwyl stedelike deelnemers 'n hoër telling vir voeding en vervoer gehad het.

Die tussengemiddelde EQ-5D VAS telling was 50 (30-80) by landelike deelnemers en 55 (20-90) by stedelike deelnemers. Die landelike deelnemers het minder probleme geopper wat met HRQoL status verband hou gegewe die omvang van selfversorging sowel as angs en dimensie.

Die deduktiewe ontleding van die kwalitatiewe inligting beskryf die lewensrolle van Xhosa vroue as selfversorging, voorsiener, versorger en gemeenskapslid. Die rolverantwoordelikhede en hoe omgewingsfaktore die aktiwiteite en take beïnvloed, is beskryf en tussen die studie-gebiede vergelyk.

Die induktiewe bevindings van die kwalitatiewe inligting beskryf die persoonlike ervarings van Xhosa vroue met beroerte in drie opkomende temas naamlik: tema 1 – “ Ek sukkel met niks nie, ander doen so baie vir my”, tema 2 – “Ek hou daarvan om nog mooi te lyk” en tema 3 – ‘Dood, maar lewendig’. Hierdie temas gee die deelnemers se persepsie mee van familie ondersteuning sowel as eie motivering en herbeplanning om in lewensrolle deel te neem.

Gevolgtrekking

Die studie vind dat lewensrolle dieselfde is in landelike en stedelike gebiede. Omgewingsfaktore beïnvloed egter die aktiwiteitsvereistes van rolverantwoordelikhede wat addisionele aanpassings verg om struikelblokke te oorkom. Deelnemers se persoonlike ervarings in beide gebiede is dieselfde en hul persepsie van sosiale ondersteuning was ‘n bydraende faktor van hulle siening van HRQoL. Die oorvleueling van inligtingsbronne in hierdie studie beklemtoon die beperking van die BI om die verbandhoudende faktore wat aktiwiteite daaglikse lewe aan te spreek en vergelykende tellings tussen bevolkings in verskillende omgewings of kulture te beskryf.

SLEUTELWOORDE: BEROERTE, AKTIWITEITE, DEELNAME, ROLLE, XHOSA, VROUE, OMGEWING, ERVARINGS, LANDELIK, STEDELIK

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“In every man [person], heredity and environment have combined to produce a creature of certain abilities and desires – including a deeply ingrained need to function in such a way that his life will be MEANINGFUL. A man [person] has to be something; he needs to matter.”

Hunter S. Thompson

Definitions of Key Concepts

Stroke

“rapidly developing clinical symptoms and signs of focal, and at times global disturbance of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin” (WHO MONICA Project Principal Investigators, 1988, p.105)

Participation

“Involvement in a life situation.” (World Health Organization, 2001, p.12)

Activity

“The execution of a task or action by an individual.” (World Health Organization, 2001, p.12)

Environmental Factors

“The physical, social and attitudinal environment in which people live and conduct their lives. These are either barriers to or facilitators of the person's functioning.” (World Health Organization, 2001, p.12)

Rural

“Sparsely populated areas in which people farm or depend on natural resources, including villages and small towns that are dispersed through these areas; areas that include large settlements in the former homelands, which depend on migratory labour and remittances as well as government social grants for their survival, and typically have traditional land tenure systems.” (National Treasury, 2011, p192):

Urban

“A continuously built-up area with characteristics such as type of economic activity and land use. Cities, towns, townships, suburbs, etc. are typical urban areas.” (Statistics South Africa, 2012d, p20)

Roles

Roles are defined as “behavioural expectations that accompany a person's occupied position or social status in a social system.” (McKenna, Liddle, Brown, Lee et al., 2009)

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List of abbreviations & acronyms

ADL's	Activities of Daily Living
ARV	Anti-Retrovirals (treatment)
BI	Barthel Index
CVA	Cerebral Vascular Accident
D&E	Demographic and Environmental (questionnaire)
EQ-5D	EuroQol 5 Dimensions questionnaire
HIV	Human Immunodeficiency Virus
HREC	Health Research Ethics Committee
HRQoL	Health-Related Quality of Life
ICC	Interclass Correlation
ICF	International Classification of Functioning, Disability and Health
KSD	King Sabata Dalindyebo district municipality
LMIC	Low to Middle Income Countries
NCD's	Non-Communicable Diseases
NGO	Non-Governmental Organisation
RDP	Reconstruction and Development Program
SSA	Sub-Saharan Africa
SSI	Semi-Structured Interview
VAS	Visual Analogue Scale
WHO	World Health Organisation

Chapter 1 Introduction

1.1 Background to the study

The incidence of stroke in low to middle-income countries (LMIC) has surpassed that in high-income countries during the first decade of the 21st century (Krishnamurthi, Feigin, Forouzanfar, Mensah et al., 2013). A health transition has been observed in LMIC, characterised by the increase of non-communicable diseases such as hypertension in parallel to the existing burden of communicable diseases such as HIV. This has led to an increase of cardiovascular diseases, including stroke (Kahn, 2011). At the same time, HIV has also been associated with an increased prevalence of young people with strokes (Syed & Sani, 2013), defined as the incidence of stroke in a person aged 45 years (Griffiths & Sturm, 2011; Marini, Russo & Felzani, 2010) or 49 (Smajlović, 2015) years and younger. This has led to more of the economically active population living many years of their lives with the vast consequences of a stroke (Martinsen, Kirkevold & Sveen, 2015).

A stroke not only affects multiple body functions of an individual, but it restricts the person's ability to participate in life roles and meaningful activities within their context (Horne, Lincoln, Preston & Logan, 2014; Maleka, Stewart & Hale, 2012). Contextual factors are a strong determinant of whether a person with a stroke can successfully re-integrate into their home and community life (Nasr, Mawson, Wright, Parker et al., 2016). Contextual factors refer to the environmental and personal factors impacting on an individual function (World Health Organization, 2001). In order for healthcare systems and services to be accessible and appropriate to the populations they serve, they must take account of contextual factors and their impact on a person's health (Martinsen, Kirkevold & Sveen, 2015). This is of particular importance in South Africa, where diverse cultures in rural and urban settings shape the individual's understanding of their health needs, as well as their opportunities to seek healthcare services (Vergunst, Swartz, Mji, MacLachlan et al., 2015).

In South Africa, Jelsma, Maart, Eide, Ka'Toni et al., (2007) found, that people with disabilities living in rural environments in the Eastern Cape had significantly lower health-related quality of life (HRQoL) scores, as assessed by the EuroQol five dimension questionnaire (EQ-5D), compared to participants in an urban environment in the Western Cape with the same level of functional difficulty. A limitation of standardised outcome measures is that they do not provide the opportunity for participants to elaborate on the factors influencing their participation,

independence and well-being (Rhoda, 2012) However, the authors of this quantitative study hypothesised that contextual factors in the rural environment contributed to lower self-reported quality of life (Jelsma et al., 2007).

Further, Wasserman, de Villiers & Bryer, (2009) report that the burden of stroke rests most heavily on women, whether they have themselves suffered a stroke, or are fulfilling the role of care-giver for a family member who has done so.

1.2 Motivation for the study

The motivation for this study grew out of my experiences as a physiotherapist in a deeply rural district hospital in the Eastern Cape, between 2008 and 2011. It was during this time that I became aware of the impact of contextual factors in shaping people's participation, particularly for Xhosa women. The migration of men from rural to urban settings to find employment has resulted in many female-headed households in rural communities. This has required women to fulfil extra roles and carry many more responsibilities on their own.

IsiXhosa-speaking women were observed frequently to be responsible for most of the physically intensive tasks within their households. Although their domestic duties were similar to those of women across many cultures, such as caring for children, preparing meals and doing the laundry, contextual factors shaped the activity and task requirements of these responsibilities in particular ways. For example, women who did not have access to running water inside their homes had to walk to open water sources to fetch water and carry it back home for domestic use. Many women who had suffered a stroke and been discharged from our hospital to their homes were unable to participate fully in their roles again, such as caring and providing for their families, as a result of the physical demands of these tasks within this rural setting.

It is from this experience that I have decided to focus this study on the participation of Xhosa women in both rural and urban areas, as they try to fulfil previous life roles and continue meaningful activities following a stroke. The comparison between rural and urban areas will highlight how a person with stroke's contextual factors in each setting, possibly influences their life roles and activity requirements.

1.3 Problem Statement

After a stroke, individuals struggle to perform meaningful activities and participate in life roles within their context (Nasr, Mawson, Wright, Parker et al., 2016). According to Anderson & Whitfield (2011) the inability to occupy one's time with the activities appropriate for one's age, sex and background is by far the most problematic experience in life after a stroke.

Frameworks such as the International classification of functioning, disability and health (ICF) (World Health Organization, 2001) assist in categorising and coding environmental barriers and facilitators influencing participation. However, the complex interaction between a person and their context, and their resulting experience of disability, are still poorly understood (Pettersson, Pettersson & Frisk, 2012). Participation should not be seen as a separate entity that can be influenced by a person's contextual factors, but as the result of the person's needs and responsibilities grounded within their context (Jahiel, 2015).

Little is known about the environmental influences on the activity requirements and participation experiences of Xhosa women following stroke in rural and urban settings and how it impacts their perceived health-related quality of life and healthcare needs.

1.4 Research question

What are the activity requirements and participation experiences of Xhosa women in relation to their life roles following a stroke in rural and urban settings?

1.5 Aims

This study aims to describe the participation of Xhosa women following stroke in terms of their life roles and related activity and task requirements, and to compare these across rural and urban settings. These women's personal experiences of attempting to return to these roles after stroke will also be described.

The purpose of the study is to increase our understanding of the impact of contextual factors on Xhosa women's participation following stroke, with the intention of informing healthcare policies and systems which promote their health-related quality of life by supporting community re-integration.

1.6 Objectives

- a) To describe and compare the demographic and stroke-related factors and environmental differences experienced by Xhosa women with stroke in rural and urban settings
- b) To describe and compare the functional ability of these women in relation to activities of daily living, as measured by the Barthel Index (BI)
- c) To describe and compare self-reported health-related quality of life (HRQoL) by these women, as measured by the EuroQol five dimension questionnaire (EQ-5D)
- d) To describe and compare the life roles of Xhosa women in rural and urban settings, and their related activity requirements
- e) To describe and compare the influences environmental factors have on the activity requirements and participation experiences of Xhosa women with stroke in rural and urban settings

1.7 Rationale

The knowledge gained by this study is intended to help healthcare providers to:

- a) Understand how contextual factors influence the task requirements of meaningful activities and participation in life roles of women with stroke, helping to shape more appropriate healthcare and rehabilitation services for this population;
- b) Understand how the environment influences participation for women with stroke, and so advocate for improved access to basic amenities and sanitation in low socio-economic settings;
- c) Develop and select appropriate outcome measures for healthcare and rehabilitation for this population;
- d) Contextualise health and social policies, systems and services, in order to provide accessible community based support for women with stroke and their households.

1.8 Study overview

In this chapter, the background, rationale and purpose of the study have been presented, and its aims and objectives outlined.

Chapter 2 presents a literature review of key concepts of this study with a focused review of the literature, demonstrating the gap in knowledge which this study aims to address.

In **Chapter 3**, the study's mixed methodology design is described, including the development and choice of data collection tools, data collection procedures, and analysis of both qualitative and quantitative data.

In **Chapter 4** the results of the study are presented, triangulating the qualitative and quantitative sources to create a comprehensive picture of findings.

In **Chapter 5** the findings of the study are discussed in relation to the research question and objectives. The specific contribution of this study to the field is highlighted.

Chapter 6 discusses the limitations and conclusion of this study, and presents recommendations for further research

2 Chapter 2 Literature Study

2.1 Introduction

This chapter presents literature and focused review that has contributed to the development of the research aims and objectives. A brief outline is given of stroke aetiology and epidemiology, in the South African context, with particular reference to the health transition underway in this country. The International classification of functioning, disability and health (ICF) is then discussed as a commonly used framework for stroke research, and critiques of this classification tool reviewed. Additional concepts from the literature are suggested to address its shortcomings. This literature review will highlight some current gaps that exist in stroke research and will further support the need for this research topic.

2.2 Stroke definition, epidemiology and health transition

The World Health Organisation (WHO) definition of stroke, which is still used today, is defined as: “rapidly developing clinical symptoms and signs of focal, and at times global disturbance of cerebral function, with symptoms lasting more than 24 hours or leading to death, with no apparent cause other than that of vascular origin” (WHO MONICA Project Principal Investigators, 1988, p.105). A stroke, also known as a cerebral vascular accident (CVA), is characterised by lesions in the brain due to vascular dysfunction, caused by either a cerebral infarction, intracerebral haemorrhage or subarachnoid haemorrhage (Sacco, Kasner, Broderick, Caplan et al., 2013).

Connor, Thorogood, Casserly, Dobson et al. (2004) established that stroke was the fourth leading cause of death in South Africa, with mortality rate higher in females compared to males. The crude prevalence of stroke in South Africa was 300/100 000 (95% CI, 250 to 357) and the prevalence of stroke in mostly rural communities in South Africa was found to be between 259/100 000 (Maredza, Bertram & Tollman, 2015) and 290/100 000 (Thorogood, Connor, Lewando-Hundt, Tollman et al., 2004).

Findings from the Global Burden of Disease study of 2010 found that the age-standardised international incidence of people with ischaemic stroke rose from 156.24/100 000 in 1990 to 163.33/100 000 in 2010, while the incidence of people with haemorrhagic stroke increased from 68.11/100 000 in 1990 to 87.41/100 000 in 2010 (Krishnamurthi, Feigin, Forouzanfar, Mensah et al., 2013).

Stroke has historically been viewed as one of the leading causes of mortality and morbidity in high income countries, however between 1970 and 2008 the incidence of stroke in high-income countries decreased by 42% (Feigin, Lawes, Bennett, Barker-Collo et al., 2009). This is in accordance with findings from the 2010 Global Burden of Disease study which reported a significant decrease in the incidence of stroke in high income countries between 1990 and 2010 (Krishnamurthi et al., 2013). In contrast to these trends, the same study demonstrated that stroke incidence in low- to middle income countries (LMIC) more than doubled between 2000 and 2008, and now exceeds that of high-income countries.

The decline of stroke incidence in developed countries could be attributed to improvements in preventative strategies (Krishnamurthi et al., 2013). The increase of strokes and other cerebral vascular disease in LMIC can be attributed to a 'health transition' (Defo, 2014; Kahn, 2011; Maher & Sekajugo, 2011; Ntsekhe & Damasceno, 2013).

Health transition is a concept used to describe and explain a series of concurrent changes in a population's health and disease patterns (Defo, 2014). These transitions are characterised by a long-term shift in mortality and disease patterns, for example the shift from epidemics of communicable disease towards a greater burden of degenerative and non-communicable diseases (Defo, 2014). Research into health transitions assists countries in the development and implementation of appropriate health and social policies (Defo, 2014; Maher & Sekajugo, 2011).

The health transition in South Africa and other sub-Saharan African (SSA) countries has been characterised by the increase of vascular risk factors for most of the population leading to an increased prevalence of stroke (Kahn, 2011; Syed & Sani, 2013). The increased incidence of stroke has been associated with the increase of non-communicable diseases such as hypertension, in parallel with communicable diseases such as HIV in South Africa (Defo, 2014; Kahn, 2011; Wasserman, de Villiers & Bryer, 2009).

In this country, the transition has been prolonged by the ongoing socio-economic disparities and polarisation between rural and urban settings (Defo, 2014; Wasserman, de Villiers & Bryer, 2009). Economic growth has led to rapid urbanization, with migrant workers travelling from rural to urban areas in search of employment opportunities (Fay, 2015; Ntsekhe & Damasceno, 2013). The sedentary lifestyles, increased stressors and unhealthy diets associated with urbanization and socio-economic growth increase exposure to cardiovascular

risk factors, and therefore stroke (Kengne & Mayosi, 2013; Maher & Sekajugo, 2011; Ntsekhe & Damasceno, 2013). Known risk factors for stroke are hypertension, history of coronary artery disease or myocardial infarction, diabetes, obesity and atrial fibrillation (Maher & Sekajugo, 2011; Norris, Allotey & Barrett, 2012; Ntsekhe & Damasceno, 2013).

A contributing factor to the complex nature of our health transition is the ongoing burden of communicable diseases such as HIV (Kahn, 2011; Maher, Smeeth & Sekajugo, 2010; Maredza, Bertram & Tollman, 2015; Tollman, Kahn, Sartorius, Collinson et al., 2008) which has also contributed to a rise in the incidence of stroke in a younger population (Kissela, Khoury, Alwell, Moomaw et al., 2012; Maredza, Bertram & Tollman, 2015; Rouillard, De Weerd, De Wit & Jelsma, 2012; Tollman et al., 2008). According to Syed & Sani (2013) Sub-Saharan Africa is home to 12% of the world's population, but carries a disproportionately large burden of disease, including 70% of all adults living with HIV in the world today. Cultural traditions, migrating workers and the disempowerment of women have been shown to contribute to the spread of HIV in SSA countries, including South Africa (Defo, 2014; Stoeckenau, Heise, Wamoyi & Bobrova, 2016).

HIV has been strongly associated with stroke, especially in a younger population (Benjamin, Bryer, Emsley, Khoo et al., 2012; Karbasi-Afshar & Izadi, 2014). Young people with strokes are defined as occurring before the age of 45 (Griffiths & Sturm, 2011; Marini, Russo & Felzani, 2010) or 49 (Smajlović, 2015) years, whereas the majority of strokes resulting from more typical cardiovascular risk factors occur much later (Sen, Rabinstein, Elkind & Powers, 2012; Smajlović, 2015; Syed & Sani, 2013).

Mortality is significantly lower among those classified as young people with strokes, which means that this group will live many more years with the consequences and burden of a stroke (Kissela et al., 2012; Martinsen, Kirkevold & Sveen, 2015). This has important implications for healthcare services, as this group comes to require longer term support and follow-up. The younger population with strokes would also otherwise be expected to be economically active and care for dependants in their households, but may be unable to return to work and participate in domestic duties (Rouillard et al., 2012). This may lead to deepening poverty and subsequent ill health and disability, which will not only affect the individual, but also place a significant burden on the whole household's health and livelihood.

2.3 Stroke and International Classification of Function, Disability and Health

The consequences of a stroke for an individual are complex, influencing communication, motor, sensory and cognitive function, which in turn restrict participation in the home and community (Anderson & Whitfield, 2011; Baseman, Fisher, Ward & Bhattacharya, 2010; Goljar, Burger, Vidmar, Leonardi et al., 2010; Maleka, Stewart & Hale, 2012; Pundik, Holcomb, McCabe & Daly, 2012; Robison, Wiles, Ellis-Hill, McPherson et al., 2009; Rouillard et al., 2012; Wasserman, de Villiers & Bryer, 2009). People with stroke have reported being unable to participate in previously meaningful activities such as returning to work, social activities and domestic duties (Anderson & Whitfield, 2011; Robison et al., 2009).

People with stroke who were previously the care-givers within their household experience a role reversal, as they are now dependant on family members to care for them (Anderson & Whitfield, 2011; Maleka, Stewart & Hale, 2012; Pundik et al., 2012; Robison et al., 2009). The consequences of stroke are seen in different domains of a person's health and function; not only in the impact on physical abilities, but also in the loss of independence and restrictions in participation, which negatively affects the emotional wellbeing of the person and their family (Rhoda, 2012).

The World Health Organisation's (WHO) International classification of functioning, disability and health (ICF) aims to provide a framework and common language for the description of health and health-related states (World Health Organization, 2001). The ICF does not measure disability, but describes the different domains of human functioning that may be affected by a health condition. It is used to describe the level of functioning, disability and health of a person beyond the disease or disorder they may have (Pettersson, Pettersson & Frisk, 2012).

The ICF consists of two parts, each with two components. The first part addresses functioning and disability, including the components of body functions and structures, and activities and participation. The second part of the ICF covers contextual factors, with the two components of environmental and personal factors. Figure 2-1 illustrates the different ICF components and the interaction between them.

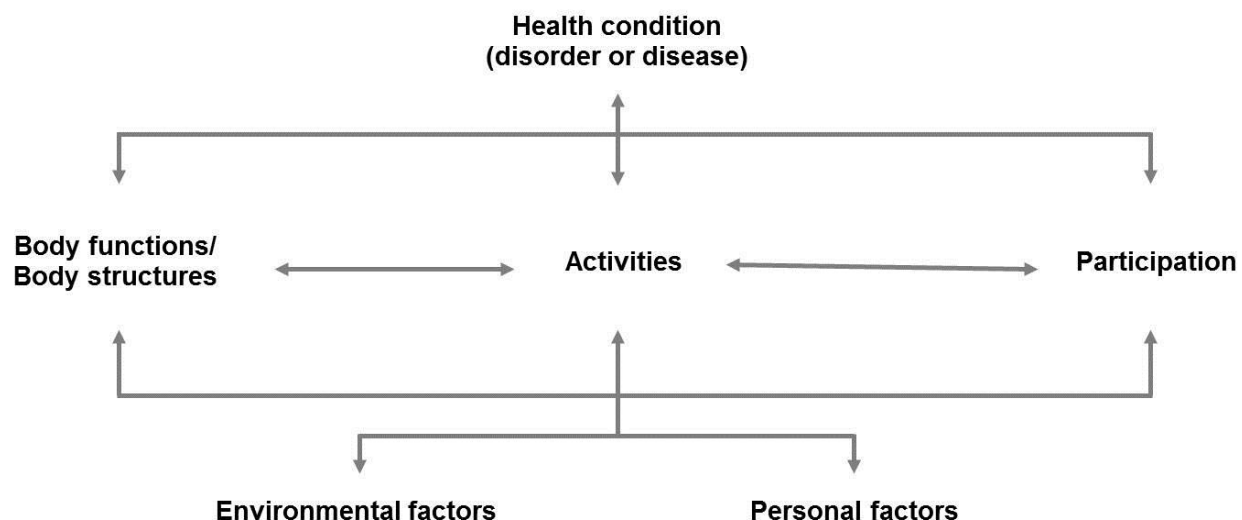


Figure 2-1 The ICF diagram illustrating interaction between different components (World Health Organization, 2001, p.26)

In the following sections, these various components will be explained with reference to the experiences of people with stroke. The ICF will then be critiqued with reference to current literature. Additional concepts from the literature were identified to address the shortcomings of the ICF framework for the purposes of the study, and these will also be outlined.

2.3.1 Body functions and structures

The ICF distinguishes between body functions and body structures, with functions referring to the physiological function of body systems, and structures relating to anatomical parts of the body such as organs and limbs. Impairments refer to problems experienced in body function and structure, as a result of a health condition (World Health Organization, 2001).

Strokes lead to brain lesions which are associated with neurological fallout and often cause impairment in body function affecting the upper and lower limb on one side, known as hemiplegia. (Ghosal, Burman, Singh, Das et al., 2014; Jellema, Sande, Hees, Zajec, et al., 2016; Laurent, De Sèze, Delleci, Koleček et al., 2011; Rhoda, 2012). Hemiplegia refers to motor and sensory dysfunction leading to abnormal muscle tone and poor selective movement, affecting the contra-lateral side of the body to the brain lesion (Sacco et al., 2013). Depending on the area of the brain lesion, cognition and speech can also be affected, which has a profound effect on the participation and social re-integration of people with stroke (Baseman, Fisher, Ward & Bhattacharya, 2010; Kruithof, Mierlo, Visser-meily, Heugten et al.,

2013; Laurent et al., 2011; McKenna, Liddle, Brown, Lee et al., 2009; Rhoda, 2012; Robison et al., 2009).

2.3.2 Activity and participation

Several studies have recommended that health practitioners should be aware of the activity limitations and participation restrictions experienced by people with stroke, in order to be able to implement holistic healthcare services that are client centred (Maleka, Stewart & Hale, 2012; Obembe & Eng, 2016; Obembe, Mapayi, Johnson, Agunbiade, et al., 2013; Piskur, Daniels, Jongmans, Ketelaar et al., 2014; Rhoda, 2012).

Activity as used in the ICF is defined as “the execution of a task or action by an individual” and activity limitations as “difficulties an individual may have in executing activities”, (World Health Organization, 2001, p.12). Participation is defined as “involvement in a life situation”, and participation restrictions as “problems an individual may experience in involvement in life situations” (World Health Organization, 2001, p.12).

2.3.3 Limitations of ICF’s activity and participation component

Although the ICF has been useful in advancing a holistic understanding of people’s health, and establishing a common language to describe health and health-related states, a number of limitations to this system have been highlighted in recent literature (Jahiel, 2015; Lundälv, Törnbom, Larsson & Sunnerhagen, 2015; Pettersson, Pettersson & Frisk, 2012; Piskur et al., 2014; Ravenek, Skarakis-Doyle, Spaulding, Jenkins et al., 2013).

The ICF has received criticism for its inadequate definition of participation, the lack of a clear distinction between participation and activity, and a grouping of factors that often presents duplications (Pettersson, Pettersson & Frisk, 2012; Ravenek et al., 2013).

Lundälv et al. (2015) recommend ongoing discussion to better establish the boundaries and interactions between the two concepts, while Jahiel (2015) suggests the use of social roles as a concept to capture participation.

Social or life roles are defined as “the behavioural expectations that accompany a person occupied positions or social status in a social system” (McKenna et al., 2009, p.177) to a person’s status is defined by the position which they occupy, carrying certain rights and obligations (Biddle, 2013; Satink, Cup, Ilott, Prins et al., 2013). We thus occupy a status and play a role.

A person can occupy more than one status, and these can also be categorised into two groups, namely achieved status or ascribed status. According to Biddle (2013) achieved statuses are acquired as a result of an individual's actions and efforts, such as qualifying as a health professional. Ascribed status is placed upon a person, usually at birth, for example being a family member, brother or sister (Biddle, 2013).

Role expectations or responsibilities can change over time and vary between different cultures (Kroger, Martinussen & Marcia, 2010). Life stages in adulthood are categorised by Armstrong (2007) as early adulthood (age 20 – 35), midlife (age 35-50), mature adulthood (age 50 – 80) and late adulthood (age 80+), with each life stage involving different roles, responsibilities and achievements. In this scheme, each life stage spans approximately fifteen years.

In early adulthood (20 – 35 years of age), a person has the responsibilities of establishing a family and circle of friends, and finding a job. Within this stage a person is seen as needing to go out into the world to make a mark for themselves. In midlife (aged 35-50) a person is usually economic active, with the additional responsibilities of raising children (Armstrong, 2007). In mature to late adulthood (aged 50 and older), a person has already raised their family, and established themselves at work. They now become contributors to society, benefitting others with their wisdom and experience (Armstrong, 2007).

These life stages have important implications for the experiences of people with stroke. A person with stroke who is within a younger life stage will struggle particularly to fulfil their roles and expectations, finding it difficult to go out into the world, interact with others and raise their children. Qualitative studies focusing on the experiences of people post stroke found participants struggling to participate in major life roles such as returning to work (Hassan, Visagie & Mji, 2012; Maleka, Stewart & Hale, 2012; Rhoda, 2012; Singhpoo, Charemtanyarak, Ngamroop, Hadee et al., 2016). According to Maleka, Stewart & Hale (2012) the inability to execute meaningful and valued activities was associated with the loss of roles by people with stroke which, in current literature, was linked to lower HRQoL and depression (Anderson & Whitfield, 2011; Horne, Lincoln, Preston & Logan, 2014; Robison et al., 2009).

2.3.4 Personal factors

As stated previously, the second part of the ICF details the contextual factors which shape a person's experience of disability and health, and is divided between personal and environmental factors. Personal factors give background to an individual's life, and include their experiences and cultural characteristics that may play a role in their disability. However, despite the WHO's frequent emphasis on health-related quality of life (HRQoL), the ICF itself excludes personal experiences relating to life satisfaction, quality of life and coping strategies (Pettersson, Pettersson & Frisk, 2012; Piskur et al., 2014; Ravenek et al., 2013).

According to Baseman et al. (2010) the overarching goal of a person with stroke is to achieve a level of autonomy similar to that which they enjoyed before the stroke, where they can make their own decisions and participate in meaningful activities.

HRQoL is described as a construct encompassing a person's subjective perceptions related to the physical, mental and social dimensions of their lives (Katona, Schmidt, Schupp & Graessel, 2015). This accords with the WHO's 1948 definition of health (cited in (Huber, Knottnerus, Green, et al., 2011), still in use today, which is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".

HRQoL is multidimensional and provides important information for healthcare policies, systems and services which seek to be accessible and appropriate for people with stroke (Chang, Sohn, Lee, Kim et al., 2016; Kruithof et al., 2013; Tang, Lau, Mok, Ungvari et al., 2014).

A person with stroke's perceived HRQoL is influenced by all the domains within the ICF, including impairments in body function, limitations in executing valued activities, participation restrictions in major life roles, and contextual factors (De Wit, Theuns, Dejaeger, Devos et al., 2016; Obembe & Eng, 2016; Rhoda, 2014). Contextual factors play a particularly important role, and include environmental factors such as social support, and personal factors, such as depression (Anderson & Whitfield, 2011; De Wit et al., 2016; Chang et al., 2016; Kruithof et al., 2013; Rhoda, 2014; Tang et al., 2014).

2.3.5 Environmental Factors

The WHO (2001) defines environmental factors as the "physical, social and attitudinal environment in which people live and conduct their lives". Anderson & Whitfield (2011) state

that it is often barriers in the environment that influence the participation of a person with stroke. The ICF further categorises environmental factors into the domains of products and technology, natural environment and human made changes to the environment, support and relationships, attitudes and services, systems and policies. These will be discussed in more detail below.

2.3.5.1 Products and technology

Products and technology entail any natural or human-made products, equipment or technology within the individual's environment which are used by persons with disabilities to promote their re-integration and participation in society (World Health Organization, 2001). Examples of products used by people with stroke would be wheelchairs, walking aids or adapted chopping boards for food preparation. Although such items are designed and manufactured to assist people with disabilities, when inappropriately prescribed and provided, they can become barriers rather than facilitators to participation. For example, wheelchairs which do not address the needs of the user within their context can have a negative effect impact on their mobility and re-integration within their community (Vergunst, Swartz, Mji, MacLachlan et al., 2015; Visagie, Duffield & Unger, 2015).

2.3.5.2 Natural environment and human-made changes to environment

This category is defined as “animate and inanimate elements of the natural or physical environment, and components of that environment that have been modified by people, as well as characteristics of human populations within that environment” (World Health Organization, 2001, p169). The natural environment encompasses physical geography, climate and air quality, among other factors. Human-made changes include buildings, roads and other physical structures that are man-made. Maleka, Stewart & Hale (2012) described the impact of physical environment on women with stroke, who described experiencing a considerable fear of falling when having to walk on rough terrain and navigate obstacles and slopes.

2.3.5.3 Support and relationships

Support and relationships are defined as “people or animals that provide practical, physical and emotional support..., assistance and relationships to other person, in either at home, place of work, school... or in any other aspect of the daily living” (World Health Organization, 2001, p172). Such support can come from family members, friends, employers or health professionals. According to Horne et al. (2014), support from family and friends reinforced

people with strokes' self-belief, and gave them the confidence to re-engage in meaningful and social activities. Due to the lack of support and rehabilitation services at community level in many communities in South Africa, family members often become primary care-givers without adequate education or training. This increases care-giver strain and decreases the wellbeing of people with stroke (Wasserman, de Villiers & Bryer, 2009).

2.3.5.4 Attitudes

Attitudes, according to the WHO (2001, p176), are “the observable consequences of customs, practices, ideologies, values, norms factual beliefs and religious beliefs.” These attitudes are not those of the person themselves, but rather those of external people, and are grouped according to the different kinds of relationships mentioned in the “support and relationships” category, e.g. individual attitudes of immediate family members. Several studies have found that people with stroke perceive the attitudes of community members as a barrier to their participation (Cawood & Visagie, 2015; Horne et al., 2014)

2.3.5.5 Services, systems and policies

‘Services’ refers to any services “designed to meet the needs of individuals”, while ‘systems’ refers to the “administrative control and organisational mechanisms... to organize, control and monitor services” and policies, “govern and regulate the systems” (World Health Organization, 2001, p180)

A systematic review by Nicholson, Sniehotta, Wijck, Greig et al. (2013) found that one of the major service-related environmental barriers limiting people with stroke's community re-integration is transportation. Public transportation services are often inaccessible and private transportation is unaffordable to many (Cawood & Visagie, 2015; McKenna et al., 2009; Nicholson et al., 2013; Rhoda, 2012)

According to Jahiel (2015), the ICF currently presents participation as an attribute of a person which might be influenced by the environment, however participation should rather be understood as the interaction between a person and their context. While the ICF addresses the different domains of function and related contextual factors, little is known about the complex interactions between these different components (Pettersson, Pettersson & Frisk, 2012). Several authors have called for revision of the graphical representation of the ICF, to better illustrate the interaction between the health condition, functioning and disability, and contextual factors (Jahiel, 2015; Pettersson, Pettersson & Frisk, 2012; Ravenek et al., 2013).

Jellema et al. (2016) and Robison et al. (2009) found that despite some personal, physical and social factors influencing participation in previously valued activities, it was not clear what the relationship was between these factors.

In their systematic review, Jellema et al. (2016) identified a range of personal, physical and social factors which influenced participants' participation in previously valued activities. It emerged from the qualitative data review that people with stroke had to be adaptable and constantly strategize to overcome barriers to participate in meaningful activities within their context. However, it was not clear from the study what the relationships between the various environmental factors and participation actually were.

2.4 A focused review: Stroke and influences of environmental factors

As discussed above, several studies have highlighted the barriers posed by environmental factors to the participation of people with stroke (Cawood & Visagie, 2015; Jellema et al., 2016). However, there remains a lack of understanding on how environmental factors influence participation, and the complex interaction between the different categories and domains (Pettersson, Pettersson & Frisk, 2012).

A focused literature review was done to further research how environmental factors influence activities and participation in people with stroke in rural compared to urban settings.

2.4.1 Methods

The purpose of a focused review was to establish differences between activities of daily living and social participation in rural and urban settings. The question for this review was: What is known about the differences in activities of daily living and social participation for people with stroke in rural compared to urban environments?

The electronic databases searched were: Medline, Cinahl, Pubmed, Scopus, Cochrane, Science Direct, Web of Science, Ebscohost, OT Seeker and PEDRO.

The search terms and keyword combinations are presented in table 2-1. The search was limited to research with humans, articles in English and participants aged 18 years and older. All study methodologies were accepted and no limitations were implemented for dates of publications.

Table 2-1 the search strategy with combination of keywords.

Search terms:
1. Stroke
2. Social participation (MESH)
3. Activity of daily living (MESH)
4. Rural
5. Urban
6. #2 OR #3
7. #4 OR #5
8. #1 AND #6 AND #7

Articles were excluded from the focused review if the study population consisted of hospital or rehabilitation centre in-patients, as these could not capture the influence of environment on study participants' residential and community re-integration. In addition, only studies presenting disaggregated data on different activities or participation outcome measures were included, as combined functional or participation scores were found to be insufficient in presenting information on specific activity limitations and participation restrictions.

2.4.2 Results

The above search yielded a total of 549 articles, which were further screened. The organisational chart in figure 2-2 illustrates the further screening process applied to the articles identified by the electronic search.

The final six articles thus identified are detailed in table 2-2, and their content presented below.

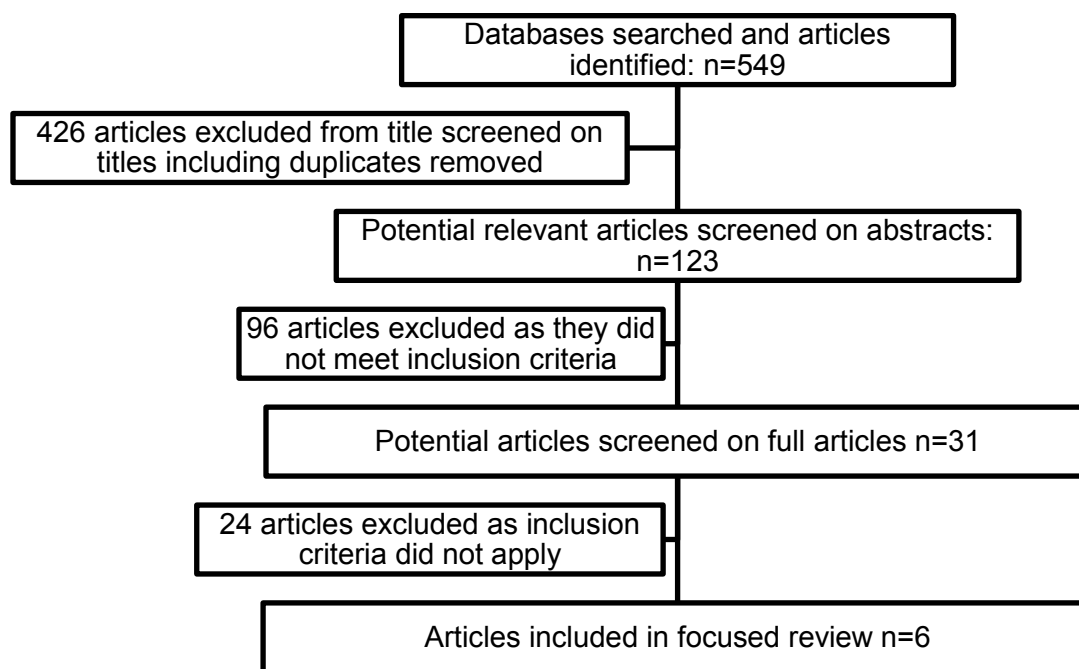


Figure 2-2 The focused review's flow and different phases conducted.

In table 2-2 the six articles included in the review to address the review question are summarised with relation to the primary author, year of publication, setting, country and other relevant information.

Table 2-2 List of articles pertaining to focused review

Primary author, year, country	Methodology	n	Average or range of age in years	Measuring Instruments
Ali, 1998, Rural Pakistan	Qualitative, observational	24	50-75 years,	Survey, observations, interviews
Norris, 2012, Rural Indonesia	Qualitative, Ethnography and Phenomenology	11	32–69 years	In-depth interviews and photographic facilitated interviews
Wasserman, 2009, Rural South Africa	Quantitative Case Series	30	68.6	Barthel Index, Modified Rankin Score, Survey
Eaves, 2000, Rural, USA,	Qualitative, descriptive	8	67.0 (56 – 79)	Semi-structured interviews and observations
Jerome, 2009, Rural and Urban France	Quantitative	61	64.0 (+/- 8.5)	Barthel Index, Instrumental activity of daily living, DSMIV-R, Survey
O'Connell, 2001, Rural Australia	Qualitative, exploratory	40	58.4 (20-89)	Five Focus Groups, semi-structured

2.4.3 Findings

Six articles were included in the review. Two of the articles used quantitative methodology and four used qualitative methodology. All of the articles reported to be conducted in rural areas except one that was conducted in rural, peri-urban and urban areas, but no distinction was made between the different data. It must be highlighted that rural setting in a high income country will differ from LMIC. Half of the articles were conducted in LMIC and the other half were conducted in high-income countries.

The six studies reported many participants struggling with self-care activities, independent mobility, returning to work and participating in social or leisure activities within their communities (Eaves, 2000; Jerome, Dehail, Daviet, Lamothe et al., 2009; Norris, Allotey & Barrett, 2012; O'Connell, Hanna, Penney, Pearce et al., 2001; Wasserman, de Villiers & Bryer, 2009).

Two studies from high-income countries reported that participants were unable to return to driving after the stroke which severely impacted on their independence and perception of disability (Jerome et al., 2009; O'Connell et al., 2001).

Two studies, with one each of a LMIC and high-income country, highlighted how study participants only accessed healthcare facilities days after the onset of stroke (Eaves, 2000; Wasserman, de Villiers & Bryer, 2009). While this could be attributed to lack of knowledge about the symptoms of stroke, two articles, also one each of a LMIC and high-income country, described problems with accessing transportation (O'Connell et al., 2001; Wasserman, de Villiers & Bryer, 2009). In the absence of rehabilitation services in some rural settings in LMIC (Wasserman, de Villiers & Bryer, 2009), several articles reported that participants were discharged back to their homes to be cared for by family members who received little education, training or support from health and social systems (Eaves, 2000; Jerome et al., 2009; Norris, Allotey & Barrett, 2012; O'Connell et al., 2001; Wasserman, de Villiers & Bryer, 2009). Only in the study conducted by Eaves (2000) in the United States of America, did participants, including those from rural settings, have access to in-patient rehabilitation services which promoted their functional independence.

Two articles from high-income countries reported that environmental adaptations were possible to improve the functional independence of people with stroke (Eaves, 2000; Jerome et al., 2009). According to Jerome et al. (2009) 26.5% of their study participants were able to

make home adaptations or move to different dwellings that were more accessible. Eaves (2000) also reported that participants could make adaptations to bathing facilities in the home to improve their independence. However, in a study in LMIC where access to healthcare and community support structures was lacking, many participants were bed-bound and often lay soiled for long periods of time, due to poor family support at home (Norris, Allotey & Barrett, 2012).

These articles give some information about the environmental barriers to independence experienced by stroke participants across various settings, as well as strategies devised to overcome them. They did not however offer more detailed insight into how the person's environment, specifically in a rural area, affects their participation and life roles after a stroke.

Only one study from Ali & Mulley (1998) aimed to investigate the relationship between the person and their environment when participating in activities of daily living after a stroke. The study's purpose was to determine whether the Barthel Index outcome measure, which assesses activities of daily living, was appropriate for people with stroke in rural Pakistan.

The researchers visited study participants at their homes, and observed how they performed the everyday activities listed on the Barthel Index. They then interviewed participants about the relevance and applicability of activities of daily living contained on the scale within their context.

The results of the study found that differences in participants' personal and environmental factors shaped the nature of each task. For example, as many of the participants practiced Islam, they would not feed themselves with their right hand even if it was the non-affected side, as this was against their customs. Participants would therefore score lower on the Barthel Index, as they would request family members to feed them rather than feeding themselves with the 'wrong' hand. This demonstrated that it was not always impairments in body function that prevented participants from performing activities, but rather the cultural and social norms within their context.

Another example related to the index item scoring participants' ability to transfer to a chair. The lack of furniture in the village dwellings meant that transfers from a chair were not required of participants in their daily lives. Many participants stayed in bed for much of the time (Ali & Mulley, 1998).

Grooming and bathing was an activity particularly influenced by the availability of products and technology and water services in their environment. Participants did not have indoor baths or showers, but only hand-operated outdoor water pumps. Bathing was done using a bucket or basin placed on a small stool, and pouring water from this bucket over themselves. Due to the nature of the tasks associated with bathing like this, many participants were dependant on others to perform the activity (Ali & Mulley, 1998).

Based on these findings, the authors suggest caution when using the Barthel Index in cross-cultural studies and for international comparisons. Their paper highlights how personal and environmental factors shape the task requirements of the activities of daily living listed in the Barthel Index. These contextual factors do not only create barriers or facilitators to participation, but actually shape the activity and task requirements for participation in social, leisure, household and self-care activities.

The focused review revealed the lack of research into the influence of environmental factors on the activity requirements of people with stroke. It is for this reason that this study focuses on describing and comparing the activity requirements and participation experiences of women with stroke in rural and urban settings. This study will focus on a specific cultural population, within South Africa, the Xhosa population, to minimise the variables associated with cultural norms.

2.5 The Xhosa population

The amaXhosa are the second largest ethnic group in South Africa (Statistics South Africa, 2012). The majority of the amaXhosa people live in the Eastern Cape, part of which was formerly designated as a 'homeland' for the Xhosa people by the Apartheid government. During this period, such homelands saw very little development and remain predominantly rural, even up until today (Fay, 2015; Neves & Du Toit, 2013).

In the rural areas of the Eastern Cape, people are dependent on subsistence farming for their livelihood (Fay, 2015; Neves & Du Toit, 2013). Agricultural tasks are generally distributed between men and women. However, due to high male migration from rural to urban environments, many households in rural areas are headed by women, who carry the bulk of household responsibilities (Fay, 2015; Matinga, 2012).

According to Ghosal et al. (2014) gendered studies of life after stroke in sub-Saharan Africa have shown that women tend to have poorer functional outcomes, with higher prevalence of

depression and limitations in activities of daily living. Other studies have shown that women who suffered a stroke have a lower HRQoL score compared to their male counterparts (Kamal, Itrat, Murtaza, Khan et al., 2009; Maredza, Bertram & Tollman, 2015). Some studies have also found the incidence (Maredza, Bertram & Tollman, 2015) and prevalence (Kamal et al., 2009) of stroke to be higher in women.

Women, in rural settings of South Africa, are seen as the main carers in households and responsible for household activities (Geere, Hunter & Jagals, 2010; Ghosal et al., 2014; Wasserman, de Villiers & Bryer, 2009). Women with stroke are at risk of having less social support and suffering neglect, as other adults in the home need to take on their household responsibilities and may even need to leave for an urban area to look for work (Ghosal et al., 2014).

Studies conducted with Xhosa people with disabilities highlight that the environment creates barriers that impact on their function and participation (Eide, Jelsma, Loeb, Maart et al., 2008; Jelsma, Maart, Eide, Ka'Toni et al., 2007). However, these studies do not describe how the environment impacts on task requirements relating to participation restrictions and activity limitations. Jelsma et al. (2007) found that IsiXhosa people with disabilities who had the same level of functional limitation had a significantly lower quality of life score if they lived in a rural environment compared to urban environment. The authors hypothesised that contextual factors could have influenced the participants' perceived HRQoL, however the study's methodology did not allow for more in-depth understanding of the relationship between the participants' perceived HRQoL and their contextual factors.

Comparing the level of function of people with stroke in rural and urban settings is not possible, due to variations in the tasks that make up activities of daily living. The previously mentioned study by Ali and Mulley (1998) unveiled how culture, religion and environment influence the execution of functional activities by a person with stroke, in a Pakistani setting. The authors concluded that care must be taken when using standardised outcome measures for comparisons of stroke-related disability between LMIC and high-income countries across different cultural and socio-economic settings.

2.6 Summary & conclusion

The incidence of stroke in LMIC has surpassed that of high income countries, which have historically been associated with a higher burden of cardiovascular disease (Feigin et al.,

2009; Krishnamurthi et al., 2013:). These LMIC, including South Africa, are experiencing a health transition which is leading to an increase in cardiovascular risk factors and incidence of stroke (Defo, 2014).

Due to the protracted nature of the health transition in South Africa, the prevalence of younger strokes is increasing due to HIV in parallel with more typical cardiovascular risk factors (Defo, 2014). A person who has a stroke at a younger age, when still expected to care and provide for their family, faces not only the challenges of a physical disability but also the mental health consequences of increased dependence on others, and resulting poor HRQoL (Martinsen, Kirkevold & Sveen, 2015; Rouillard et al., 2012).

For healthcare services to deliver accessible and appropriate services and programmes, it is essential that they understand healthcare users and their context (Jellema et al., 2016). The ICF assists with categorising the different domains that affect the health and health-related states of persons with stroke (World Health Organization, 2001). However, the definition of participation and the understanding of relationships between the different components of the ICF, such as activity and participation, environmental and personal factors are still limited (Pettersson, Pettersson & Frisk, 2012). It has been proposed that the fulfilment of social roles be used to represent participation (Jahiel, 2015), and this suggestion has been taken up for the purposes of this study.

The burden of stroke has often fallen on women (Maredza, Bertram & Tollman, 2015). In South Africa, women in rural settings are often forced to take on the role of head of household, due to migration of men from rural to urban areas (Fay, 2015). In the Xhosa population, there is a high number of female-headed households, where women have multiple roles and responsibilities to fulfil (Matinga, 2012).

These roles and activity requirements are often influenced by contextual factors (Jellema et al., 2016; McKenna et al., 2009). Health care policies and services must be contextually appropriate, in order to address, support and improve the community re-integration and HRQoL of Xhosa women following a stroke (Obembe & Eng, 2016; Baseman et al., 2010).

Outcome measures help to monitor and evaluate whether interventions are effective in addressing the needs of the person with stroke (Okoye, Odole, Odunaiya, Akosile et al., 2016). The majority of outcome measures used in stroke rehabilitation were developed in high income countries, which limits their appropriateness in rural settings (Okoye et al., 2016).

Outcome measures that take account of the South African setting are needed (Maleka, Stewart & Hale, 2012). To assist in this process, it is important to have an in-depth understanding of the person with stroke within their context and how this shapes their activity requirements and life roles (Okoye et al., 2016).

Stroke rehabilitation has previously focussed on independence in activities of daily living, but a person with stroke's HRQoL is multidimensional, and this needs to be considered in a holistic approach to rehabilitation (De Wit et al., 2016). HRQoL for people with stroke is strongly associated with participation in meaningful activities and previously valued roles (Anderson & Whitfield, 2011; Obembe & Eng, 2016). Stroke rehabilitation should be able to contextualise activities and participation, in order to address these needs.

Previous studies concerning people with stroke in South Africa have quantified their HRQoL (Jelsma et al., 2007; Rhoda, 2014), and environmental barriers to participation (Eide et al., 2008). A few studies have assessed the experiences of people with stroke (Maleka, Stewart & Hale, 2012; Rhoda, 2012), but none have addressed the relationship between the person and their context in determining meaningful activities associated with participation in life roles. This study aims to build on this existing research, through further investigation of the relationship between contextual factors, activity and participation experiences, with respect to the life roles of Xhosa women with stroke in rural and urban settings.

3 Chapter 3 Methodology

3.1 Introduction

In this chapter the study's methodology, including the study design, setting and population, is discussed. The choice, development and piloting of data collection tools and procedures are outlined, and data analysis procedures described. The role of the research assistant, ethical considerations and rigor of the study are also discussed

3.2 Study Design

This is a descriptive, cross-sectional study, which used a convergent mixed methods design. This design was chosen to best answer the research question: "What are the activity requirements and participation experiences of Xhosa women in relation to their life roles following a stroke in rural and urban settings?"

A descriptive study is used to capture specified characteristics of a study population, and a cross-sectional design gives a snapshot of a population at a specific point in time. Cross-sectional studies are often used when assessing the healthcare needs of a population (Pluye & Hong, 2014). This study provides a personal picture of Xhosa women with stroke as they describe their perceived life roles, associated activity requirements, and their personal experiences of fulfilling those life roles in rural and urban settings.

Mixed methodology refers to the combined use of both quantitative and qualitative research methods in a study. The strength of this study design is in providing a more in-depth and complete understanding of the research question, by collecting different but complementary data (Bentahar & Cameron, 2015; Creswell, Klassen, Plano Clark & Smith, 2011; Guest, 2013; Pluye & Hong, 2014). It can provide stronger conclusions through corroboration of findings by multiple data sources. This study followed a convergent mixed methodology design, which involves the collection and analysis of two independent strands of quantitative and qualitative data at the same time (Creswell et al., 2011; Migiro & Magangi, 2011; Pluye & Hong, 2014). Data from rural and urban settings were first analysed separately and thereafter the results were compared side-by-side.

Qualitative data in healthcare research can give an in-depth understanding of participants' perceptions of their disease, disability and function (Bentahar & Cameron, 2015; Creswell et al., 2011; Guest, 2013; Migiro & Magangi, 2011; Pluye & Hong, 2014). In the overall

interpretation of the study results, complementary qualitative and quantitative data were compared, to look for convergence, divergence or contradictions, and to triangulate and confirm findings (Bentahar & Cameron, 2015; Creswell et al., 2011; Guest, 2013; Pluye & Hong, 2014).

Quantitative data is effective in determining, categorising and quantifying desired information by using closed-ended questions from different measuring tools such as standardised outcome measures and questionnaires (Bentahar & Cameron, 2015; Creswell et al., 2011; Guest, 2013; Migiro & Magangi, 2011; Pluye & Hong, 2014). In this study, standardised outcome measures and a questionnaire were used to measure participants' levels of independence in activities of daily living, health-related quality of life (HRQoL) and environmental barriers encountered. On its own however, this data cannot provide a detailed understanding of participants' experiences and perceptions of their life roles, and the ways in which contextual factors shape their role-related activity requirements (Migiro & Magangi, 2011; Rhoda, 2014).

In the convergent design adopted here, the quantitative and qualitative data were collected in a single stage, and only analysed once data collection was complete. Sequential mixed method designs allow for qualitative and quantitative data to be collected in successive stages, with the findings of each stage shaping the subsequent one (Creswell et al., 2011; Migiro & Magangi, 2011; Pluye & Hong, 2014). While this might have been of value in this study, it was impractical due to resource limitations, and rural participants' difficulties in travelling to a central point for data collection. This highlights a potential weakness in many mixed methods designs, which can be expensive and time-consuming to carry out (Migiro & Magangi, 2011).

By converging both quantitative and qualitative data, a comprehensive level of understanding of this research topic can be provided. This allows for recommendations on future research and advocacy for women with stroke who share similar characteristics with this study population.

3.3 Study population

In this section the population researched in this study is discussed, and the characteristics of participants eligible for this study are described.

The study population is Xhosa women with stroke living in the rural and urban setting and are represented by study participants in the rural setting of the Eastern Cape, KSD municipality and urban setting of the Western Cape, City of Cape Town Metropole. IsiXhosa speakers form the second largest ethnic group in South Africa, accounting for 16.0% of the total population, while the larger isiZulu-speaking group accounts for 22.7% (Statistics South Africa, 2012c). The largest percentage of isiXhosa speakers (78.8%) reside in the Eastern Cape, with 24.7% in the Western Cape (Statistics South Africa, 2012c). During the Apartheid regime, part of the Eastern Cape was designated as the homeland of the Xhosa people, and was known as the Transkei (Fay, 2015; Neves & Du Toit, 2013). These homelands were underserved, with limited development and economic activity in their rural areas, which contributed to high unemployment rates (Fay, 2015).

In the Western Cape, during the apartheid regime, relatively informal settlements were built for migrant workers, such as Khayelitsha, which still has limited infrastructure and adequate municipal services (Legg & Penn, 2013) which impacts on activities of daily living. The dense population living low socio-economic settings and informal settlements in the City of Cape Town Metropole gives rise to high incidences of communicable diseases including HIV and Tuberculosis (Legg & Penn, 2013; Smit, De Lannoy, Dover, Lambert et al., 2015). The environmental factors in low socio-economic areas in the Western Cape have also been recognised to have an impact on the increase of non-communicable disease and cardiovascular risk factors, as the problems with food security and limited safe spaces to conduct physical exercise (Smit et al., 2015).

Today, continued high unemployment rates in rural areas such as the Eastern Cape result in the migration of the economically active population, especially men, to urban areas to find work (Fay, 2015; Statistics South Africa, 2012c). This contributes to a high percentage of female headed households of 57.3% in the KSD municipality, compared to 38.2% in the Cape of Cape Town Metropole (Statistics South Africa, 2013). This percentage can be expected to be even higher in the rural parts of KSD, outside the city of Mthatha where the majority of employed people in the municipality reside.

Xhosa women are often responsible for labour-intensive work related to domestic duties (Geere, Hunter & Jagals, 2010). Women have also been identified to be at a greater risk of carrying the burden of a stroke, either by suffering a stroke themselves or being the primary

care-giver for a family member with stroke (Kamal, Itrat, Murtaza, Khan et al., 2009; Maredza, Bertram & Tollman, 2015).

The focus of this study is the differences in activity requirements and participation experiences as experienced by women with stroke in relation to their life roles in a rural compared to urban setting. As people with stroke often struggle to perform basic activities of daily living, it is important to understand the heavy burden of social, economic and practical responsibilities carried by Xhosa women within their households and communities. The results of the study will assist in advocating for the development and contextualisation of healthcare policies and services to address the needs of this population.

3.3.1 Inclusion criteria

The study sample included Xhosa women with stroke:

- (a) Who were 18 years old or older at the time of selection,
- (b) Who presented with typical unilateral neurological fallout on observation,
- (c) Who had suffered only one stroke and had no prior disabilities,
- (d) Who had had the stroke a minimum of six months and a maximum of ten years before the time of this study and
- (e) Who had lived in their current location for at least six months before the stroke

The second and third criteria sought to ensure a reasonable similarity in body function impairments between participants. The third criterion, together with the fifth, also ensured that participants had an experience of normal functioning in their activities of daily living and social roles in their current context, prior to the stroke. The lower limit on time since stroke aimed to exclude women who were still in the early stages of adjustment to stroke, while the upper limit ensured that participants remained in the same life stage as defined by Armstrong (2007) as they had been prior to stroke.

3.3.2 Exclusion criteria

Participants were excluded if they:

- (a) Suffered from cognitive, mental health, physical, visual or any other impairments and limitations before the stroke that hindered their independence in activities of daily living and participation in residential and community roles before the stroke.

- (b) Needed a proxy to complete the questionnaire or standardised outcome measure due to receptive, expressive or global aphasia or impaired executive functions.

The latter criterion was introduced because the EuroQol five dimension questionnaire (EQ-5D) has not been validated for completion by a proxy, as a second person's perception of the participant's HRQoL may be biased. Communication disorders in people with stroke have a significant influence on their participation and HRQoL. However, assessing and addressing the effect of communication disorders on participation and activity requirements was beyond the scope of this study.

3.4 Study Setting

The study was conducted in rural and urban environments where a majority Xhosa population live. As rural environments are characterised by poor socio-economic conditions, the urban study site was chosen to match. The two study sites were purposefully chosen based on the researcher's familiarity with both, through her work as a primary health care physiotherapist in OR Tambo district and the Cape Metropole. The study sites display typical characteristics of rural and urban settings as defined by local and international literature, supporting the transferability of study findings. The two research settings are described and compared below.

3.4.1 Rural Setting

Rural areas in South Africa are characterised by sparsely populated land with small villages or towns, where the population is mainly dependent on farming, social grants and migrant labour for survival (Fay, 2015; Maredza, Bertram & Tollman, 2015; National Treasury, 2011; Neves & Toit, 2013). Such areas are often former homelands, which are also characterised by traditional communal land tenure systems (Fay, 2015; National Treasury, 2011).

3.4.1.1 Location

The rural site chosen for this study was the Mqanduli sub-district of King Sabata Dalindyebo (KSD) municipality of O.R Tambo district in the Eastern Cape Province. This area formed part of the former Transkei homeland allocated to the Xhosa people during the Apartheid era. Today 98.4% of the population in O.R Tambo District is isiXhosa speaking (Statistics South Africa, 2012b). Figure 3-1 shows the O.R. Tambo district highlighted in red within the Eastern Cape in relation to South Africa.



Figure 3-1 O.R. Tambo, highlighted in red in the Eastern Cape of South Africa

3.4.1.2 Type of municipality

The KSD sub-district includes two urban areas surrounding the towns of Mthatha and Mqanduli, but 95% of its households are located in rural areas (Statistics South Africa, 2012a). O.R. Tambo is a rural category C2 municipality, indicating a largely rural area with a low urbanisation rate (National Treasury, 2011).

3.4.1.3 Demographics

The average household size in KSD municipality is four people (Statistics South Africa, 2013). The total dependence ratio, which refers to the proportion of people under the age of 15 and over 65, in relation to the economically active population aged 15 to 65, is 80.5 for the OR Tambo district (Statistics South Africa, 2013). This illustrates a high percentage of a dependent population as compared to the national average of 52.7 (Statistics South Africa, 2013).

3.4.1.4 Economic Activities

The economically active age group, defined as falling between 15 and 65 years of age, accounts for 59,9% of the population. The unemployment rate in KSD municipality is 38.3%, but among the youth (15 – 34 years of age) this reaches 48.3%, which is higher than the national average of 29.8% (Statistics South Africa, 2012a; Statistics South Africa, 2013). It is likely that the unemployment rate outside the municipality's two towns is much higher than

this average. The high percentage of dependent population, alongside a high rate of unemployment, contributes to the dependence of most households in this region on government assistance (social security) and subsistence farming (Fay, 2015; National Treasury, 2011; Neves & Toit, 2013).

3.4.1.5 Environment

KSD municipality is characterised by traditional homesteads consisting of round mud huts with thatched roofs and limited amenities such as piped water, toilets connected with sewerage and electricity for lighting. Only 19.1% households in this municipality have piped water inside the dwelling, which is well below the national average of 83.5% (Statistics South Africa, 2012a). Only 26.1% of households have a flush toilet connected to a municipal sewerage system. The availability of piped water and flush toilets in the rural areas could be much lower, but specific statistics were not available. The remainder of households rely on communal pit latrines (Statistics South Africa, 2012a). Seventy-two percent (72%) of households in the KSD municipality have access to electricity for lighting and 57.5% for cooking (Statistics South Africa, 2012a). Alternative fuel sources for lighting are candles and paraffin, and wood fires and paraffin stoves are used for cooking.

3.4.1.6 Summary

The rural study site was characterised by traditional dwellings with limited and in some cases no amenities such as running water, flush toilets and access to electricity for cooking and lighting. These environmental factors contribute to additional tasks which rural households have to complete to obtain water, cooking fuel and access to toilets. The population in this rural setting is largely dependent on government grants for survival.

3.4.2 Urban Setting

Urban areas are characterised by towns with a high population density and extensive development of infrastructure, including business and industrial districts. Most of the urban population has non-agricultural jobs (Statistics South Africa, 2013).

3.4.2.1 Location

The urban site chosen for this study was the Cape Metropole in the Western Cape, specifically three areas characterised by a high percentage of Xhosa residents, and poor socio-economic conditions. The areas chosen were Khayelitsha, Du Noon and Delft. Figure 3-

2 illustrates, in red, the location of the Cape Metropole within the Western Cape province of South Africa



Figure 3-2 City of Cape Town metropole within the Western Cape, South Africa

According to Statistics South Africa (2013), isiXhosa speakers account for 96.8% of the population in Khayelitsha, 64.7% in Du Noon and 37.8% in Delft (Statistics South Africa, 2012b).

3.4.2.2 Type of municipality

The Western Cape is one of the wealthiest provinces in South Africa and comprises mainly well-developed urban areas. The City of Cape Town is one of the six category A municipalities in South Africa, defined as urban areas with high population density and extensive development, including centres of economic activity (National Treasury, 2011).

3.4.2.3 Demographics

The average household size is 3.3 in Khayelitsha, 2.7 in Du Noon and 3.8 in Delft (Statistics South Africa, 2012b). The total dependence ratio for the City of Cape Town metropole is 43.6 (Statistics South Africa, 2013), slightly lower than the national average of 52.7% and much lower than the 80.5% of rural areas (Statistics South Africa, 2013). This reflects the higher

proportion of economically active population in the metropole compared to rural areas. This can be explained by the influx of migrant workers to the City of Cape Town Metropole, many from the Eastern Cape.

3.4.2.4 Economic activities

Despite the high proportion of economically active population, unemployment rates are still high in the Cape Metropole, with 38.1% in Khayelitsha, 36.7% in Du Noon and 41.3% in Delft, compared to a national average of 29.8% (Statistics South Africa, 2012b).

3.4.2.5 Environment

The study site is characterised by a mix of formal and informal housing, with only 44.6% of the population in Khayelitsha, 40.9% in Du Noon and 82.5% in Delft living in formal dwellings. The remainder live in the large informal settlements, mostly in shacks built from corrugated iron, plastic and timber (Legg & Penn, 2013; Statistics South Africa, 2012b).

Households which have access to piped water in their dwellings or in their yard constitute 61.7% in Khayelitsha, 65.8% in Du Noon and 87.3% in Delft (Statistics South Africa, 2012b). The majority of the population in the Cape Metropole has access to a flush toilet that is linked to a water-borne sewerage system, with 71.5% in Khayelitsha, 72.2% in Du Noon and 89.6% in Delft (Statistics South Africa, 2012b).

The majority of black residents in low socio economic areas in the Cape Metropole have access to electricity for lighting (80.7% in Khayelitsha, 76.4% in Du Noon and 94.0 % in Delft (Statistics South Africa, 2012b). The percentage of black population that has access to electricity for cooking fuel is 75.1% in Khayelitsha, 74.5% in Du Noon and 92.3% Delft (Statistics South Africa, 2012b).

3.4.2.6 Summary

The urban study site was characterised by a large population of migrant workers from rural areas. Despite the high percentage of economically active population, there is a high unemployment rate among people in urban study settings. Urban areas do have increased access to running water, flushed toilets and access to electricity for lighting.

3.5 Research Assistant

A research assistant was employed to assist with translation of research tools, data collection, transcription of interviews, and translation of transcriptions. The same research assistant participated in data collection in both the rural and urban study sites.

The criteria in selecting the research assistant were as follows:

- (a) She must be a Xhosa woman, fluent in the language and with an understanding of the Xhosa culture.
- (b) She should have experience of life in both rural and urban areas
- (c) She must have experience in disability research, rehabilitation or facilitation of support groups in the Eastern or Western Cape.
- (d) She must have completed matric and have basic computer skills.

The research assistant appointed grew up and went to school in the former Transkei homeland in the Eastern Cape. After high school, she moved to Cape Town, where she worked as a support group facilitator, community disability worker for an NGO, and later an auxiliary social worker. She is trained in the field of disability and has participated in previous research studies focusing on disability.

The research assistant was trained by the researcher on the background of the study, ethical aspects and the various instruments to be used. Specific aspects covered in the training included:

- The type of study,
- Aims and objectives of the study,
- Ethical principles and documentation, specifically completion of written informed consent.
- Procedural protocol for the study,
- Quantitative data collection tools, which included the demographic and environmental (D & E) questionnaire and standardised outcome measures (Barthel Index, EQ-5D) and,
- The qualitative interview schedule, and how to facilitate semi-structured interviews.

After an initial pilot of the semi-structured interview guide and data collection procedure, constructive feedback was given to the research assistant by the researcher regarding her facilitation and translation of the semi-structured interviews. The researcher was always

present during data collection and any queries or concerns raised by the research assistant were discussed for joint problem-solving.

3.6 Recruitment of Participants

The flow diagram in Figure 3-3 illustrates the steps taken to recruit participants in both rural and urban study sites. More information is provided on each step in the recruitment process below.

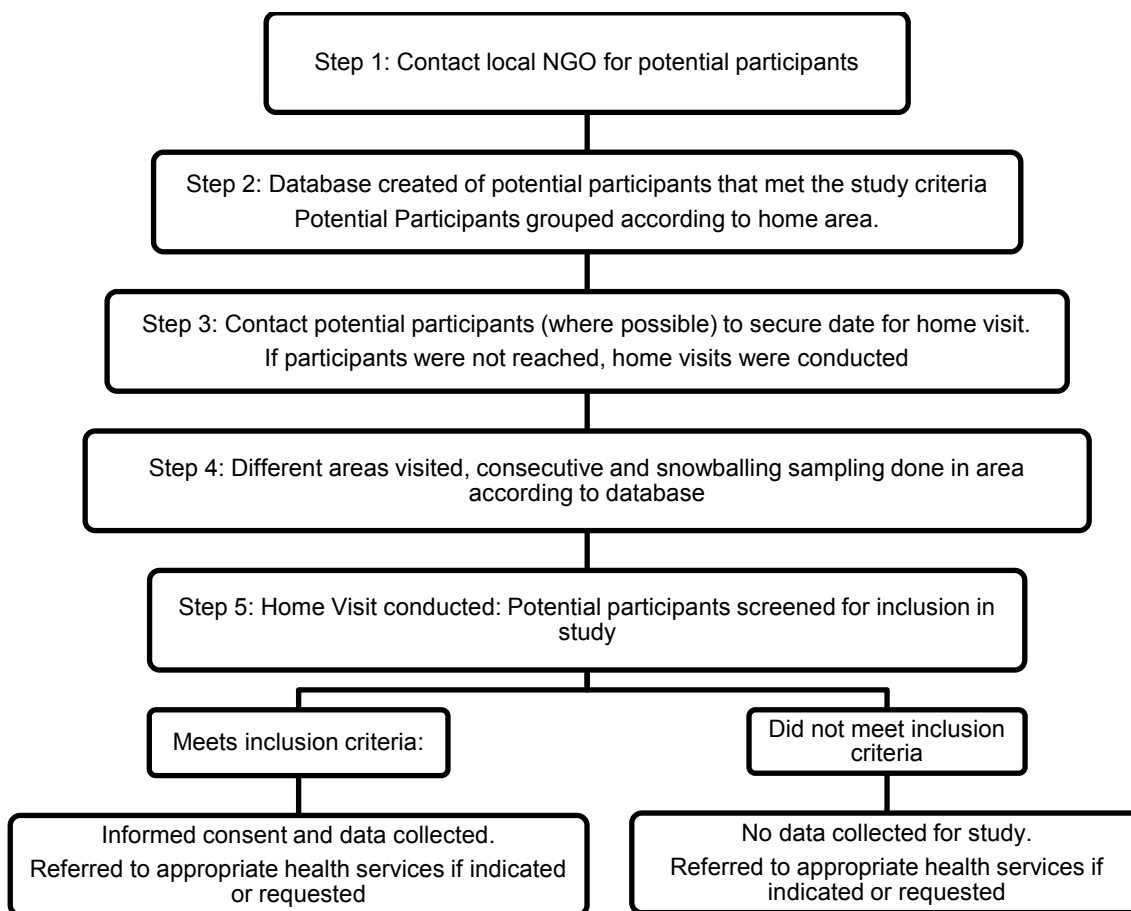


Figure 3-3 Recruitment of participants

Non-governmental organisations (NGO's) working in the field of disability were contacted in both sites to generate a database of women meeting the criteria for the study. A standard email was sent to the organisations to explain the aim of the study and what it would entail, with study synopsis and proof of ethical clearance by the Stellenbosch University Health Research Ethics Committee (HREC) attached (Appendix 1).

Four NGOs were identified and contacted at the rural site, and only one responded and agreed to assist with this study. Seven organisations were contacted in the urban study

setting and four responded to communication. Two organisations did not respond to any communication. In total, three organisations agreed to assist with this study. Two of the organisations who responded, could not assist with study: one because it was withdrawing from the community due to loss of funding, and one because it did not have contact with women meeting the study criteria, but the other three agreed to be involved.

The NGO at the rural site employs community-based rehabilitation workers who visit people with disabilities in their different communities and assist with their residential and community re-integration. The urban NGOs are involved in providing home-based care services and running community support groups for people with disabilities and their families. One of these organisations runs advocacy programs for people with disabilities.

The participating organisations were asked to follow their own internal protocols and use discretion in identifying and approaching potential participants from among their beneficiaries. Contact information for these women was then shared with the researcher. This was important both for the organisations' compliance with the Protection of People's Information Act of 2013 (Republic of South Africa, 2013), and to avoid hostility towards the researchers during home visits.

Community workers from the NGOs or community members associated with NGO programs accompanied the researcher and research assistant to participants' homes. At the homes, the researcher would introduce herself and the research assistant in isiXhosa. The research assistant would then explain the reason for the visit and if appropriate, request permission to speak with the family member listed in the database. Information was given to potential participants about the study. Because it was assumed that some of the women might be illiterate, this was explained verbally in isiXhosa by the research assistant.

A series of questions was asked to screen the participant for eligibility and where possible, their responses were confirmed with family members. Clinical observations were made by the researcher to confirm the nature of neurological fallout and any communication or cognitive difficulties.

Table 3-1 The screening questions for study eligibility

- 1) How old are you?
- 2) Have you had a stroke?
- 3) When did you have the stroke?
- 4) How long did you live in this area before the stroke?
- 5) Do you have any communication problems that might limit your participation in this study?
- 6) Did you have any problems before the stroke which limited your ability to participate in activities in your home or community?

Any questions raised by the participants about the study were addressed. Informed consent was first obtained verbally from participants who met the criteria, and written consent forms (Appendix 2) were then discussed. A checklist was used to ensure all ethical aspects were covered (Appendix 3), including permission to record semi-structured interviews, and participants' right to withdraw at any time. The consent forms were signed by the study participant, researcher and research assistant. If participants could not sign, their right thumb print was taken instead. Family members or community health workers signed as witnesses on the consent forms. The participant and researcher each kept a copy of the signed consent form. Data collection was conducted in the participant's home language of isiXhosa or the language they preferred.

The same process of recruitment and consent was followed in the rural and urban sites. Where a potential participant refused to be involved or did not meet the inclusion criteria, the research team would inquire into any needs arising with which they might assist, for example through referral to healthcare or social support services. If indicated, an appropriate referral letter was written and the research team departed, thanking the family for their co-operation.

As the researcher had not worked at the rural site for several years, a meeting was scheduled with a physiotherapist, occupational therapist and medical officer from the local district hospital to determine referral systems and clinic outreach dates. A list of dates for physiotherapy and occupational therapy outreaches to clinics was also received for referral of participants as needed.

3.7 Sampling

The researcher and research assistant scrutinised the databases provided by the organisations, which consisted of either a Microsoft Excel spreadsheet or Word document with names, addresses and some contact numbers of potential participants. Potential study participants were grouped according to their home area to facilitate logistical and transport arrangements for the researchers.

The sample size calculation conducted indicated that a total of 42 participants, with 21 from each setting, would be required for statistical significance of measured differences and generalisability of quantitative results. This sample size was unfortunately not reached due to limited resources for data collection.

As the database of potential participants gathered from each site was relatively small, consecutive sampling was implemented from the databases, including snowballing to recruit further candidates. Home visits were conducted consecutively to potential participants according to their residential areas. Each household was asked whether they knew anyone else in the area who had had a stroke. If additional people were identified, these would be added to the database and visited to establish their eligibility for inclusion in this study. Data collection continued until all available candidates had been assessed for inclusion, within the limits of available resources.

In the rural site, a total of 15 people were screened for inclusion, but four were excluded from the study because of:

- (a) Aphasia (1),
- (b) Diagnosis not a stroke, i.e. peripheral neuropathy (1) and general joint pain (1) and,
- (c) More than 10 years since the stroke (1)

In the urban site, a total of 20 people were screened for inclusion but eleven were excluded because of:

- (d) Gender (5),
- (e) Incorrect diagnosis (3), i.e. TB spine (1), rheumatoid arthritis (1) and spinal cord injury (1)
- (f) Aphasia (2) and,
- (g) More than 10 years since the stroke (1)

A total of 20 participants met the inclusion criteria of this study, with eleven participants in the rural setting and nine in the urban setting.

3.8 Data Collection Tools

In this section, all data collection tools used in this study are discussed. The quantitative and qualitative data collection tools were chosen in order to adequately and comprehensively answer the research question: “What are the activity requirements and participation experiences of Xhosa women in relation to their life roles following a stroke in rural and urban settings?”. The processes of developing the D&E questionnaire and semi-structured interview guide are explained.

The D&E questionnaire provided demographic and stroke-related information, including information on certain environmental factors within the participants’ context.

Quantitative data was collected to assess participants’ independence in activities of daily living, their HRQoL, a score representing their personal experiences of living with a stroke, and different health state dimensions influencing their HRQoL such as problems experienced with pain including their perceived anxiety and depression.

The qualitative data aimed to determine the perceived life roles of study participants, obtain descriptions of the activity requirements to fulfil role responsibilities, and capture study participants’ personal experiences of living with stroke.

3.8.1 Demographic and Environmental Questionnaire

To answer the research question, it was important first to determine and compare the demographic info and environmental characteristics of each setting. A questionnaire (Appendix 4) was designed to gather information relating to the participants’ demographic and environmental factors in an efficient and standardised way.

The demographic information gathered in the questionnaire included age, marital status and length of time since stroke. The participants’ co-morbidities and medication were recorded to determine underlying reasons or risk factors for stroke. These were self-reported by the participants as the researcher did not have access to their medical records. Participants’ access to governments grants was assessed, to determine whether they received financial support.

The D&E questionnaire was developed in English by the researcher and study supervisor, based on the objectives of the study and using the environmental domains of the ICF as a guideline to ensure comprehensiveness. The ICF checklist was not used as this instrument has been found difficult to understand by people with limited formal education, as in rural areas in South Africa (Maart, Eide, Jelsma, Loeb et al., 2007; Pettersson, Pettersson & Frisk, 2012).

It was anticipated that some participants would be illiterate, and therefore the D&E questionnaire was completed by the researcher and research assistant through a structured interview with each participant.

The following sections detail how the domains of the ICF's environmental component were included in the D&E questionnaire which was developed for the study.

3.8.1.1 Products and technology

Participants were asked what assistive devices had been issued to them by a healthcare professional, which assistive devices they used, and whether they felt a need for further assistive devices.

3.8.1.2 Natural environment and human made changes

Information was gathered relating to the terrain around their dwellings and in the community. Further environmental information was gathered through observations during the data collection home visits by the researcher.

3.8.1.3 Support and relationships

Information was gathered on the women's main caregivers, their relationship to the study participant and whether they were paid.

3.8.1.4 Attitudes

This domain was not addressed in the questionnaire, but rather during the SSI as perceptions as attitudes experienced in their household and community could be better captured using open ended questions.

3.8.1.5 Services, systems and policies

Information was gathered relating to the type of dwellings participants lived in, what municipal amenities (electricity, water sources) and sanitation infrastructure they had access to; what cooking fuel was most often used, and whether participants could access transport services,

as well as the type of transport used. Lastly, data on the type of healthcare services regularly accessed and which healthcare providers were seen were also collected.

Additional information regarding participants' activities and physical abilities was also collected within the questionnaire in order to triangulate with data from the BI, EQ-5D and SSI. This included their ability to mobilise in their home and community; as well as information on whether the study participants looked after adult family members or children. Information as to the types of household and community activities the participants performed before and after the stroke was also gathered.

The D&E questionnaire was translated into isiXhosa by the research assistant. The isiXhosa version of the survey was then back-translated into English by an independent isiXhosa-speaking person who was not involved in developing the questionnaire. The researcher and research assistant reviewed the back translation, and deemed that no changes to the original translation were necessary.

The D&E questionnaire included some open-ended qualitative questions, which resulted in a large number of variables that needed to be captured and analysed. It is proposed that future questionnaires developed should rather focus on close-ended questions to restrict the number of variables and allow for more effective analysis of data.

3.8.2 Quantitative Data Collection Tools

3.8.2.1 Barthel Index

In this study, the Barthel Index (BI) was used to obtain information regarding the level of independence of study participants in activities of daily living. The BI (Appendix 5) is used to assess the ability of a respondent to perform basic activities of daily living in ten domains, namely: feeding, bathing, dressing, grooming, transfers, mobility, climbing stairs, accessing a toilet, and bladder and bowel control. Respondents are given a score out of 100. The higher the score, the greater the respondents' independence in activities of daily living. The BI was completed through self-reporting by participants. Collateral information was gathered from family members where possible.

The reliability and validity of the BI has been thoroughly researched and it is widely used in research on stroke (Duffy, Gajree, Langhorne, Stott et al., 2013; Quinn, Dawson, Walters &

Lees, 2009; Quinn, Langhorne & Stott, 2011). The BI has also been used in studies with isiXhosa speaking populations in South Africa (Rouillard, De Weerd, De Wit & Jelsma, 2012).

BI scores have been found to closely correlate (Pearson's $r \geq 0.78$, $p < 0.0001$) with other 'gold standard' outcome measures such as the Fugl-Meyer motor assessment (which measures impairment), and the Berg balance scale, (which measures balance) (Hsueh, Lee & Hsieh, 2001). The BI has also been found to have significant inter-rater reliability of $r=0.849$ ($p<0.001$) (Rouillard et al., 2012).

In this study, the purpose of this outcome measure was to determine and compare levels of function in activities of daily living of rural and urban participants.

3.8.2.2 The EuroQol five-dimension questionnaire (EQ-5D)

The EQ-5D (Appendix 6) is one of the most commonly used participation outcome measures assessing HRQoL, and has been used with people with various pathologies, including stroke (De Wit, 2016; Hassan, Visagie & Mji, 2012; Obembe, Mapayi, Johnson, Agunbiade et al., 2013; Rouillard et al., 2012). HRQoL is complex and multi-faceted in nature, and is influenced by impairments in body function, the ability to perform meaningful activities and participation in life roles (Anderson & Whitfield, 2011; Laurent, De Sèze, Delleci, et al., 2011; Obembe & Eng, 2016).

The EQ-5D assesses five domains that influence a participant's perceived HRQoL, namely: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. It uses a Visual Analogue Scale (VAS), on which participants rate their experiences within the five domains. Other participation and HRQoL scores were reviewed, but the EQ-5D has been translated to Xhosa and been tested. Jelsma, Mkoka, Amosun, & Nieuwveldt (2004) tested the reliability and validity of the EQ-5D isiXhosa version, and found an interclass correlation (ICC) of 0.63 ($p<0.001$) for the EQ-5D VAS (Jelsma et al., 2004). All other subdomains of the EQ-5D compared to gold standard counterparts had a statistically significant ICC score (Jelsma et al., 2004). This confirms the EQ-5D as valid and reliable for the study population, and an appropriate outcome measure for the purposes of this study.

3.8.3 Qualitative Data Collection

Semi-structured interviews are one of the most widely used interview styles in qualitative research (Doody & Noonan, 2013). This style of interview provides structure to obtain

information from different participants on the same topic, but allows freedom for further clarification (Holloway & Wheeler, 2013). Interviews give a contextual account of participants' experiences and perceptions (Doody & Noonan, 2013) which was appropriate in this study to gain a better understanding of the participants' perceived life roles, the activity requirements to fulfil these roles in own context and their personal experiences of living with stroke.

An interview guide was designed for the semi-structured interviews (Appendix 7) to ensure information was gathered consistently with each study participant.

The interview started with an open-ended question: "What are you struggling with now that you used to do before?" This question aimed to gather information on the participant's perception of changes in life roles and activity limitations following the stroke. Prompting questions were then asked to gain clarity on these restrictions and limitations.

Follow-up questions were asked to unpack participation relating to: self-care, roles as a carer (looking after family members or children), leisure activities, work or employment, religion, community meetings/responsibilities, cooking, bathing, mobility, toileting, transport and perceived support from family and community members.

Responses to these questions were intended to triangulate data from the standardised outcome measures (BI and EQ-5D) and the D&E questionnaire, and to facilitate a richer contextualised understanding of the participants' activity requirements and personal experiences of fulfilling their role responsibilities.

3.8.4 Piloting of Data Collection Tools and Procedure

In this section the D&E questionnaire and semi-structured interview guide is discussed. The pilot of the data collection procedure as a whole and the necessary changes made are also discussed. A timeline of this study is included from development of data collection tools to data collection.

3.8.4.1 Pilot of Demographic and Environmental Questionnaire

The final version of the D & E questionnaire was piloted with two isiXhosa women living in the Cape Metropole to check clarity of questions and ease of use. It would have been beneficial to pilot the questionnaire in a rural setting as well, due to possible differences in rural participants' education levels, but this was unfortunately not feasible. During the pilot, the women understood all the questions and could answer them appropriately. No changes were

deemed necessary nor made. No problems were experienced during data collection in the rural or urban setting and all questions were understood and could be answered

3.8.4.2 Pilot of Semi-Structured Interview

The semi-structured interview guide used by the research team was piloted at the rural site in the Eastern Cape. It was hypothesised that if the rural women were able to understand the questions, despite contextual differences, it would likely also be appropriate for the urban site.

The interviews were conducted in isiXhosa by the research assistant, with the facilitation of the researcher. The researcher could understand isiXhosa, but was not proficient enough to conduct the interviews herself. The interview guide offered space for researcher and research assistant to make notes and write down informal observations which assisted in the transcriptions and translation of the SSI. These research assistant notes and intermittent translation between researcher and research assistant ensured that the researcher could competently follow the conversation and facilitate appropriate follow-up questions.

The first two participants struggled to answer the original opening question in the semi-structured interview, which was phrased as: “How has your life changed since the stroke?” The question was too broad and participants struggled to give context to interpret it. The question was therefore changed to: “What are you struggling with now that you used to do before?” This question offered more context to the participants and they could immediately start talking about their perceived participation restrictions and activity limitations.

3.8.5 Pilot of Data Collection Procedure

The entire data collection procedure, including qualitative and quantitative components, was piloted in the Eastern Cape, to determine the order in which data collection tools were to be completed, ensure effective time management and test voice recording equipment.

Figure 3-4 provides the sequence of the initial data collection procedure and the adapted data collection procedure accepted and implemented after the pilot. It was initially planned that during data collection the D&E questionnaire was to be completed first, followed by the standardised outcome measures and lastly the semi-structured interviews. However, during completion of the D&E questionnaire and standardised outcome measures, participants naturally began discussing their different activity limitations and role responsibilities. These would then not be repeated during the interview at the end of the session. It was therefore

decided to conduct the SSI first, followed by the D&E questionnaire and standardised outcome measures. This worked well and the same data protocol was followed during data collection in the rural and urban settings.

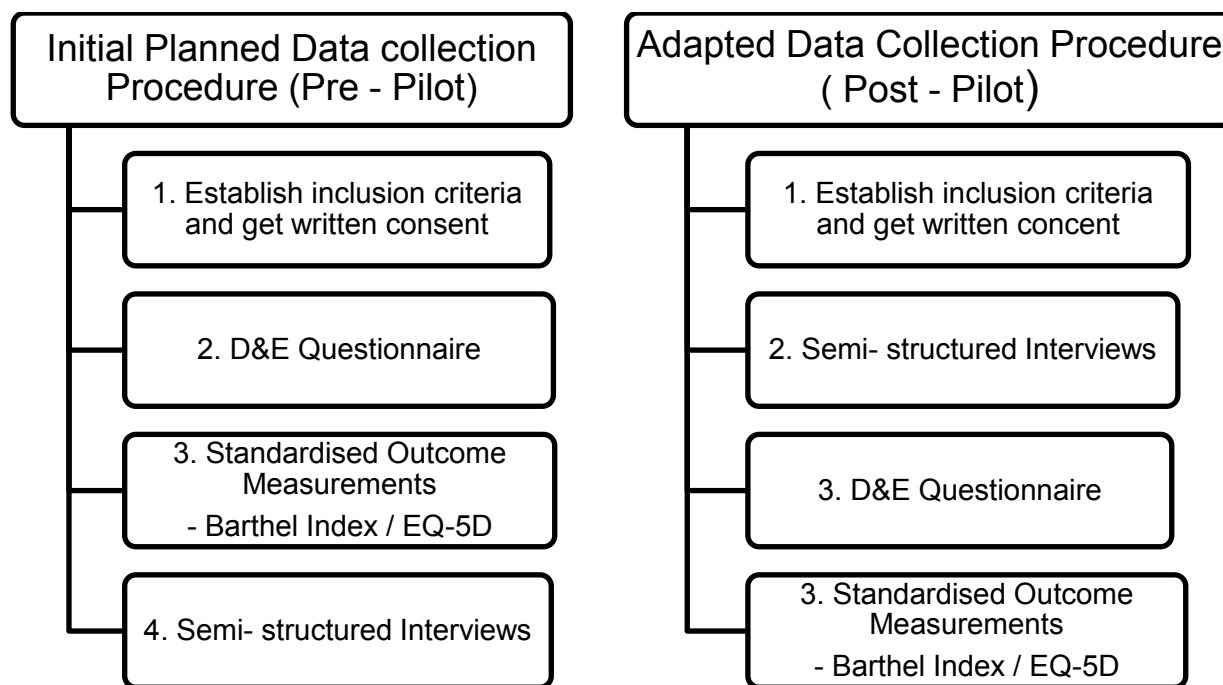


Figure 3-4 Original and adapted data collection procedures

A data collection procedural checklist was drafted by the researcher to ensure consistent execution of the protocol with each participant. (Appendix 3).

To ameliorate the barriers associated with access to transport, home visits were conducted to all rural and urban participants.

The data collection procedure outlined in figure 3-4 was then followed

3.8.6 Study timeline

Figure 3-5 illustrates the time line of the study, from the development of the D&E questionnaire and interview guide, and pilot of instruments and procedures, to the data collection itself.

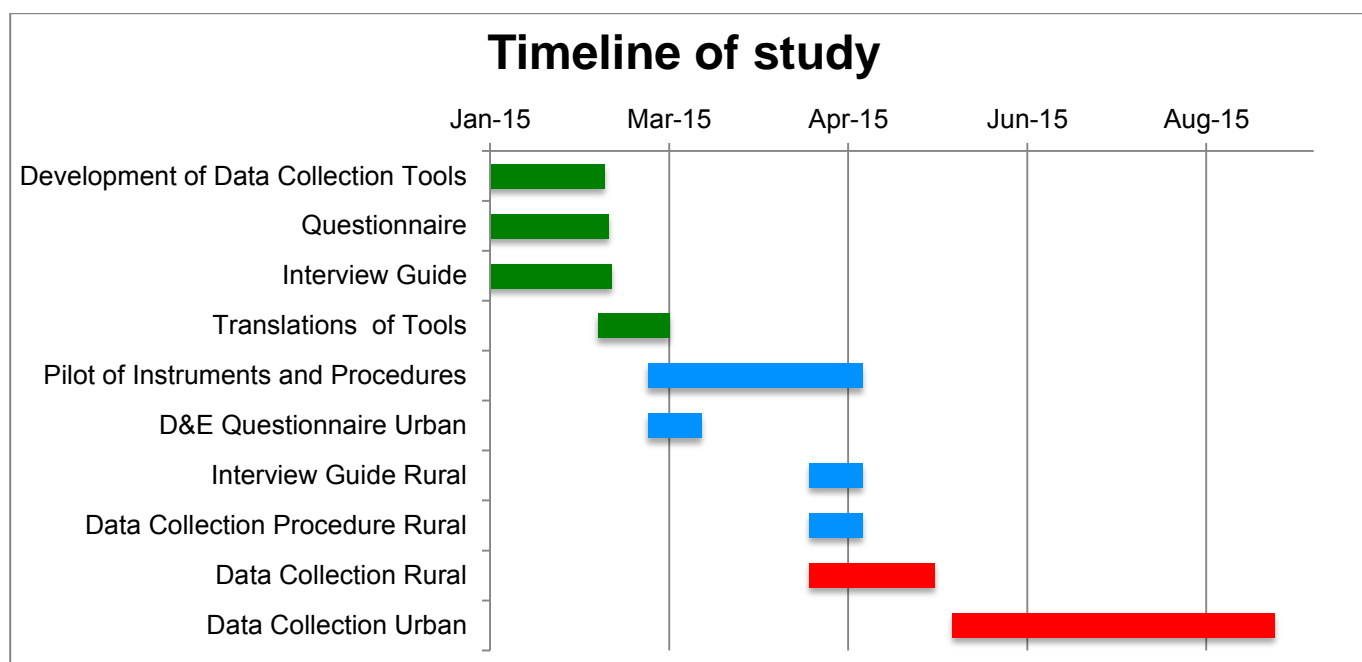


Figure 3-5 Timeline of data collection

As can be seen from the study timeline, the data collection period was shorter in the rural compared to the urban study site. Data collection at the rural site was conducted over two weeks, while at the urban site, data collection was conducted on one day a week for a period of three months.

3.9 Data management

Data obtained from participants was kept confidential and their privacy was protected. The anonymity of all study participants was assured by allocating a number to each study participant, for use on all data collection tools and research records. All information obtained from standardised outcome measures and D&E questionnaires were placed in an envelope and sealed after the session was concluded. The sealed envelopes were kept by the researcher and stored in a safe place.

The semi-structured interviews were recorded using a digital voice recorder. Voice recordings' numbers were written on the sealed envelope, and the voice recordings uploaded onto the researcher's computer. Data compiled on the researcher's computer was password-protected and only viewed by the researcher, research assistant, statistician and study supervisors.

The data was then organised and prepared for analysis. All interviews except one were conducted in isiXhosa. The voice recordings were transcribed verbatim by the research

assistant, who was also present during the interview, in MS Word. The isiXhosa transcriptions were then translated collaboratively into English by the researcher and research assistant. The interview conducted in English was transcribed by the researcher. The finished transcriptions were prepared in MS Word for coding, which involved uniform styles and spacing.

3.10 Data Analysis

The procedures followed for the analysis of quantitative and qualitative data is explained in this section.

3.10.1 Analysis of quantitative data

Microsoft Excel (version 2016) was used to capture the data from the D&E questionnaire, Barthel Index and EQ-5D. Microsoft Excel and STATA 14 were used to analyse the data.

Summary and descriptive statistics were used to describe the variables of the D&E questionnaire, Barthel Index and EQ-5D. Medians were used as the measures of central tendency for ordinal or continuous responses as the sample size was small and outliers would compromise the means (McCluskey & Lalkhen, 2007). The ranges were used as indicators of data spread.

Correlation co-efficient was done to compare the EQ-5D VAS score and total Barthel Index scores of all study participants, of the rural participants and lastly for the urban participants. This was to determine if the participants' level of independence in activities of daily living correlated with their perceived HRQoL VAS score. A p-value of 0.05 was selected to determine statistical significance.

Due to the small sample size, the quantitative findings were not statistically generalizable, but only representative of the sample itself. The sample size limited further statistical analysis.

3.10.2 Analysis of qualitative data

The qualitative data was analysed using Creswell's six steps of qualitative data analysis (Creswell et al., 2011, p.247). These are summarised in figure 3-6, and described further below.

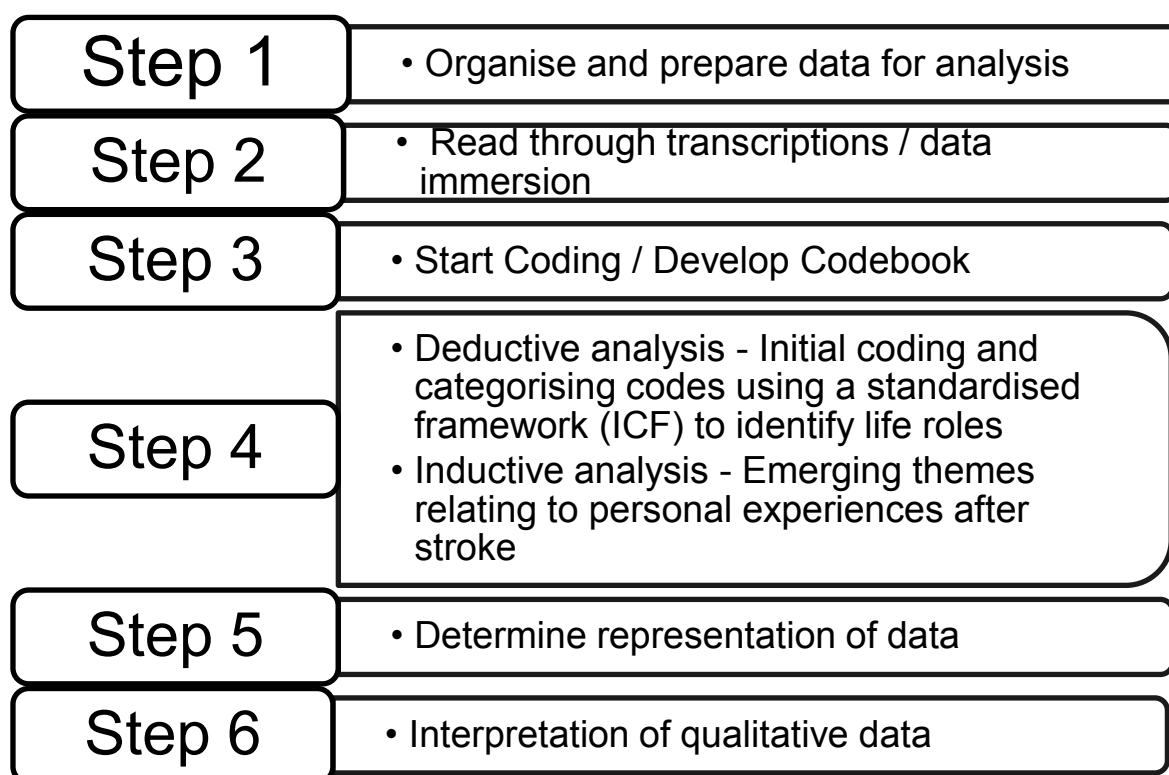


Figure 3-6 Summary of Six Steps Implemented for the Analysis of Qualitative Data (Creswell et al., 2011, p.247)

3.10.2.1 Step 1: Organise and prepare data for analysis

Following the data management processes described in the previous section, the finished transcripts were uploaded into qualitative analysis software, Atlas.ti (version 7.5.13 in Windows 10). Two hermeneutic units in Atlas.ti were created, one for the rural and one for urban transcriptions.

3.10.2.2 Step 2: Immersion in the data

The transcriptions were read several times by the researcher. Notes were made on emerging codes during the translation of the transcriptions and while reading through final documents.

3.10.2.3 Step 3: Begin coding

The rural and urban transcriptions were coded and analysed both deductively and inductively. Coding and analysis were completed in several phases, adding different layers of coding as the researcher immersed herself in the data.

3.10.2.4 Step 4: Deductive and inductive analysis

The first phase of coding was done deductively, and sought to answer the aspect of the research question concerning the different activities Xhosa women performed to fulfil life roles. Deductive analysis refers to the use of an existing framework to test, define or categorise qualitative data (Creswell et al., 2011; Vaismoradi, Turunen & Bondas, 2013). Although a framework or template was not decided when coding was conducted, the researcher used the ICF activity and participation components to categorise quantitative data. Further phases of coding related to the women's environmental factors influencing the participants' activities and participation.

All the codes were listed and defined in a qualitative codebook (Appendix 8), which was reviewed by a second reviewer (study supervisor) in order to reach consensus on meaning and interpretation of codes.

3.10.2.5 Step 5: Representation

Once the data had been coded into descriptions of activities, environmental factors influencing participation and the subjective experiences of women with stroke, a further round of analysis identified instances of successful participation (coded "facilitator") and of participation restriction (coded "barriers") across all three groupings.

Using the software's co-occurrence tool, cross-tabulations were performed of all codes across the primary document that co-occurred with the "barrier" and "facilitator" codes. The two lists of co-occurring codes were exported to MS Excel 2016 and reviewed by the researcher and peer reviewers (study supervisors). If any codes were queried within the group, the quotations were reviewed and changes made to codes within the software. After the review and corrections, final co-occurrence outputs were generated and exported to MS Excel 2016.

The codes which co-occurred with the code "barriers", indicating an inability to perform an activity, were then categorised deductively, according to the domains listed within the ICF component of activity and participation, namely:

- (a) Communication
- (b) Mobility including walking and transportation
- (c) Self-care
- (d) Domestic life, including acquisition of goods and services, preparing meals, doing housework, caring and assisting others

- (e) Major life areas such as employment or education activities
- (f) Community, social and civic life

This process yielded rich descriptions of the ICF-listed activities on the context and experiences of Xhosa women with stroke. The ICF framework assisted in grouping activities into the different responsibilities described by participants, such as having to prepare meals, attending community activities and providing shelter. These responsibilities were then further organised into emerging life roles, which were defined as the self-care role, provider, caregiver and community member. The set of roles determined by the researcher from the data was reviewed by the study supervisor, and further discussed with the co-supervisor, as a means of peer review. Together, the group agreed on the overarching life roles of self-care, provider, caregiver and community member, as a comprehensive description of the women's participation as captured in the data.

A conceptual framework emerged from the deductive analysis to structure the differences between participation, as represented by roles and role responsibilities, and activity, represented by activity and task requirements to fulfil role responsibilities. Each role thus included different responsibilities, for example within the role of provider, participants had the responsibilities of providing shelter and the acquisition of goods. Figure 3-7 uses the example of the role of provider to illustrate this hierarchy and the differences between activity and participation as experienced by participants.

Each role responsibility included different activity requirements that needed to be performed in order to fulfil the life roles. For example, within the role responsibility of providing shelter, activity requirements in the rural setting included making mud bricks and preparing grass for thatching. These activities entailed different task requirements, for example to make mud bricks, participants had to walk over rough terrain to fetch water and mud, carry it back home, hoe the soil mixture and then make the bricks.

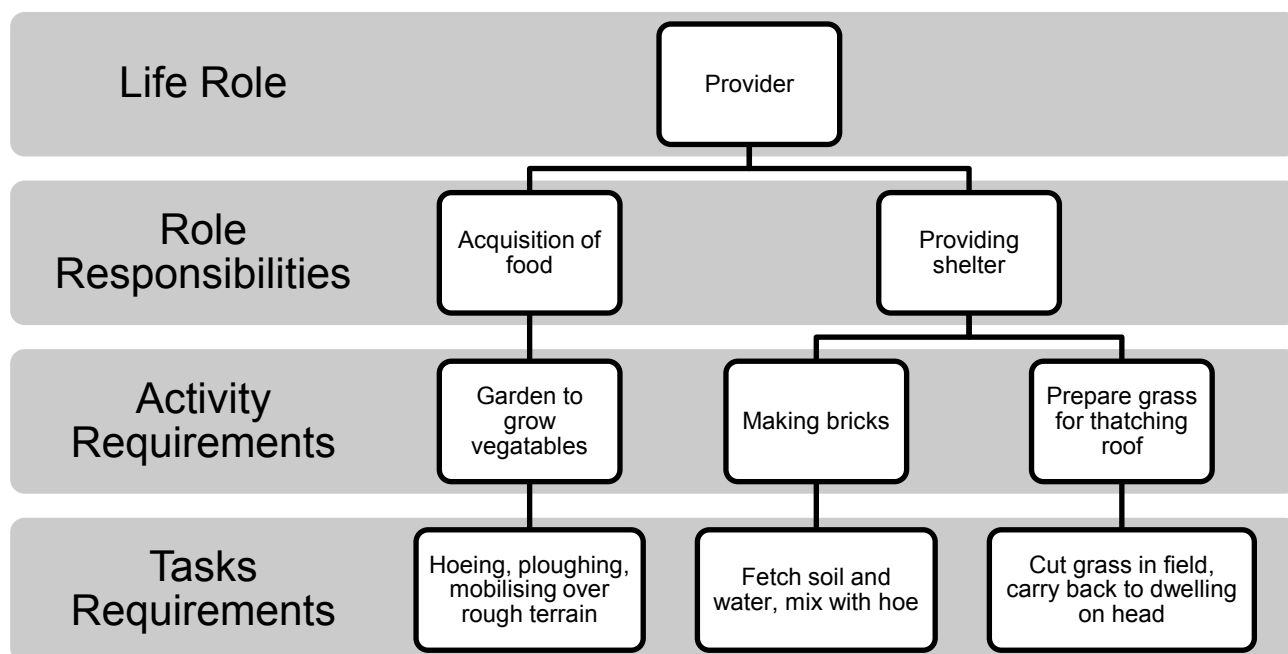


Figure 3-7 Conceptual framework: hierarchy of life roles, role responsibilities, and their activity and task requirements

The final phase of the data analysis involved an inductive analysis of the personal experiences of the participants in relation to fulfilling life roles after the stroke. Inductive analysis refers to the approach of allowing codes and categories to arise directly from the data, without any pre-existing framework in mind (Creswell et al., 2011; Vaismoradi, Turunen & Bondas, 2013).

An iterative process was used to group together similar personal and emotional experiences of the participants to form categories. Constant comparison was used to develop different categories into emerging themes which were distinct from each other. The emerging themes gave a description of the participants' personal perceptions of living with a stroke within their context.

It became evident that each participant could be identified with one particular theme, which typified their experience of life after stroke. Only two participants seemed to overlap into more than one theme, which was then discussed with the second reviewer (co-supervisor) and consensus were reached on the category into which each was placed.

3.10.2.6 Step 5: Representation of the data: descriptions and themes

The conceptual framework developed for deductive analysis was used to report on the descriptions of the participants' role responsibilities, including the activity and task

requirements. The description of the environmental factors and how they influenced the task and activity requirements was also presented. Representation of the qualitative data followed the following sequence:

- (a) Description of the life roles and role responsibilities?
- (b) Description of the activity and task requirements to fulfil life roles in participants' context
- (c) Description of the influences of environment on the fulfilment of life roles and activity requirements
- (d) Description of emerging themes relating to personal experiences of living with stroke

3.10.2.7 Step 6: Interpretation of data

The emerging themes, life roles and activities were compared side-by-side with complementary quantitative data to get a better understanding and triangulate the data. The interpretation of the qualitative data, triangulated with complementary data sources from this study, is discussed in chapter 5.

3.10.3 Point of interference between quantitative and qualitative data

In this study, different but complementary sources were used to gain an in-depth understanding of the research topic. Once the qualitative and quantitative data had been separately analysed, the various sources were combined in order to compare and triangulate findings.

Table 3-2 summarises the various data sources associated with different components of the ICF.

Table 3-2. Triangulation of data sources according to ICF components

	D&E Questionnaire	Barthel Index	EQ-5D	Interviews
Activities of daily living in the household	X	X	X	X
Impairments in body function	X	X	X	X
Environmental factors	X			X
Personal Factors	X		X	X

The triangulation of the different data sources gives a rich description of the activity requirements and personal experiences of Xhosa women with stroke, as influenced by their impairments in body function and environmental factors.

3.11 Ethical Considerations

This section describes the ethical considerations and procedures implemented during the study. The research met all ethical standards outlined in the Declaration of Helsinki (World Medical Association, 2013) and the South African Guidelines of Good Clinical Practice (Department of Health, 2006).

Ethical clearance for the study was obtained from the Health Research Ethics Committee (HREC) of Stellenbosch University's Faculty of Medicine and Health Sciences, (HREC reference number: S13/08/156 (see Appendix 1). The key ethical considerations for the study are outlined below.

3.11.1 Autonomy

Informed consent was obtained as described in section 3.6. Potential participants were informed that their participation in the study was voluntary, they could exercise their autonomy by withdrawing at any time, or declining to participate.

Data obtained from participants was kept confidential and their anonymity was protected as described in section 3.10. The research assistant also signed a confidentiality agreement not to disclose any information of participants to any third party.

3.11.2 Beneficence and Respect for Human Rights

This study did not present any risks of physical harm for the participants. However, the general well-being of participants took precedence over the aim and objective of this study. Participants were referred to appropriate healthcare or social support services if the need was identified during the study.

For example, one candidate who did not meet the study's inclusion criteria was found to have a drop foot (an impairment in the active movement of the ankle and foot) which caused her to fall when walking on rough terrain. She was referred to the physiotherapy outreach service at her nearest clinic for assessment for an ankle-foot orthosis.

3.11.3 Non-maleficence

Home visits were made for data collection with rural participants, as travel to a central point was felt to be too burdensome for the women who experienced mobility difficulties, even should the financial costs of travel be covered by the researcher.

3.11.4 Truth telling

The researcher had no conflict of interests in this study which might compromise the trustworthiness of the data. The study limitations were listed to ensure truthful representation of the data. Feedback on the study findings will be given to participating organisations which can then be shared with participants.

3.12 Rigor in quantitative and qualitative data

The following procedures were implemented to increase the rigor, reliability, validity and trustworthiness of this study's findings.

3.12.1 Quantitative data

The extensive validity and reliability testing of the standardised outcome measures has been discussed in section 3.8.2.

Due to the small sample size, the external validity of the quantitative data is limited and these findings could not be generalised to the bigger population. Sampling bias also limited the representativeness of the sample. As only NGOs could assist in identifying participants, it did limit the number of participants the research team could access, and the type of support these women were likely to be receiving. For example, in the rural study population a higher percentage of participants said that they received physiotherapy services at the clinic compared to urban participants. These findings could not be generalised from the sample to the population as the NGO used in identifying potential participants was very closely linked to rehabilitation services at local hospitals.

Bias that could occur due to inter-rater and observer reliability in this study was limited as the same researcher and research assistant conducted data collection in the rural and urban setting. The same data collection procedures were also implemented, according to the guideline developed.

3.12.2 Qualitative data

In determining the quality of qualitative research, the quantitative definitions for validity and reliability are not appropriate (Savin-Baden & Major, 2013) and the concept of trustworthiness is instead used to describe quality in qualitative research. (Elo, Kääriäinen, Kanste, Pölkki et al., 2014). The different aspects and components of trustworthiness are dependability, confirmability, credibility and transferability (Elo et al., 2014; Houghton, Casey, Shaw & Murphy, 2013; Savin-Baden & Major, 2013).

3.12.3 Dependability and confirmability

Dependability is often compared to the concept of reliability used in quantitative research (Houghton et al., 2013) which refers to the consistency of the research process during data collection, analysis and interpretation of findings (Savin-Baden & Major, 2013). This was ensured in the study through use of procedural checklists and data collection guides.

Confirmability is closely linked to dependability, and refers to the degree to which the findings can be confirmed and corroborated by other researchers. Strategies used to ensure confirmability of the qualitative components of the study were reflexivity and creation of a detailed audit trail.

Reflexivity is a process that helps the researcher to consider their position (Savin-Baden & Major, 2013) and contributions (Houghton et al., 2013)) to the research process. In this study, the researcher was a white female, which could influence the participants' ability to relate and open up to her during the SSI. However, after the researcher had introduced herself and the research assistant in isiXhosa, she would explain that she is a physiotherapist who used to work in that setting, demonstrating to the participants her understanding of their health conditions and familiarity with their context. The research assistant, who was an isiXhosa-speaking black woman, assisted in building the relationship with participants during informal dialogue before the start of the SSI.

An audit trail was created with detailed descriptions of decisions made and activities carried out during the entire research process and analysis.

3.12.4 Credibility

Credibility refers to the value and believability of the findings (Houghton et al., 2013) and that the findings represent some sense of reality from the participant's perspective (Savin-Baden & Major, 2013).

Member checking was carried out verbally throughout the interviews to ensure descriptions and experiences expressed by participants were correctly understood by the researcher and research assistant (Creswell et al., 2011; Houghton et al., 2013). The data collection took place during one contact session with the study participants. A sequential study design could have given the researcher and research assistant more time to analyse and reflect on the findings after the first phase of data collection, and to present their impressions to participants for critique during the next phase of data collection. Unfortunately, limited financial resources and time meant that this was not feasible.

By working together with the research assistant in the translation and transcription of the interviews, the researcher was able to compare understandings and check meanings with her as a key informant on Xhosa culture, and a research peer. Further peer review took place during the data analysis, as the research supervisors played the role of second and third reviewers as categories and constructs emerged.

Qualitative findings were triangulated with complementary data sources from the D&E questionnaire and quantitative data from the BI and EQ-5D to enhance the credibility of the study findings.

Peer debriefing was implemented between researcher and research assistant after each data collection to reflect on what was discussed during the interview (Creswell et al., 2011; Houghton et al., 2013).

3.12.5 Transferability

Transferability refers to the extent to which the findings of the study can be generalised or transferred to other populations or settings (Houghton et al., 2013; Savin-Baden & Major, 2013). The transferability of study findings is influenced by whether sufficient and appropriate data was obtained and triangulation used (Creswell et al., 2011; Hammell, 2002). The qualitative findings of this study were triangulated with complementary data from other sources such as the D&E questionnaire, BI and 5Q-5D.

3.13 Conclusion

This study's descriptive mixed methodology design involved collecting in-depth, contextualised data from participants using the same data procedures and data collection tools in two different settings. The analysis of quantitative and qualitative data has been outlined. The ethical considerations pertaining to this study in accordance with the Declaration of Helsinki (World Medical Association, 2013) and the South African Guidelines of Good Clinical Practice (Department of Health, 2006) have been discussed. The results of the quantitative and qualitative data will be presented in Chapter 4 and further discussed in Chapter 5.

4 Chapter 4 Results

4.1 Introduction

This chapter outlines the results of the study, including both quantitative and qualitative data. The findings from the D&E questionnaire are presented in the first four sections, followed by the data from the Barthel Index and the EQ-5D. Finally, the qualitative data from the semi-structured interviews (SSI) are presented.

4.2 Demographic and stroke related information of rural and urban participants

The sample size calculation determined that a total of 42 participants with 21 in each setting would be required to find significant differences and generalise the quantitative data results. This sample size was unfortunately not met due to lack of resources available during data collection. The following results should therefore be interpreted with caution.

In the rural setting a total of 15 people were screened for inclusion, but four were excluded from the study. In the urban environment, a total of 20 people were screened for inclusion but eleven were excluded. A total of 21 participants met the inclusion criteria of this study; with eleven participants in the rural setting and nine in the urban setting respectively.

The map in figure 4-1 illustrates the distribution of rural participants within the KSD municipal borders.

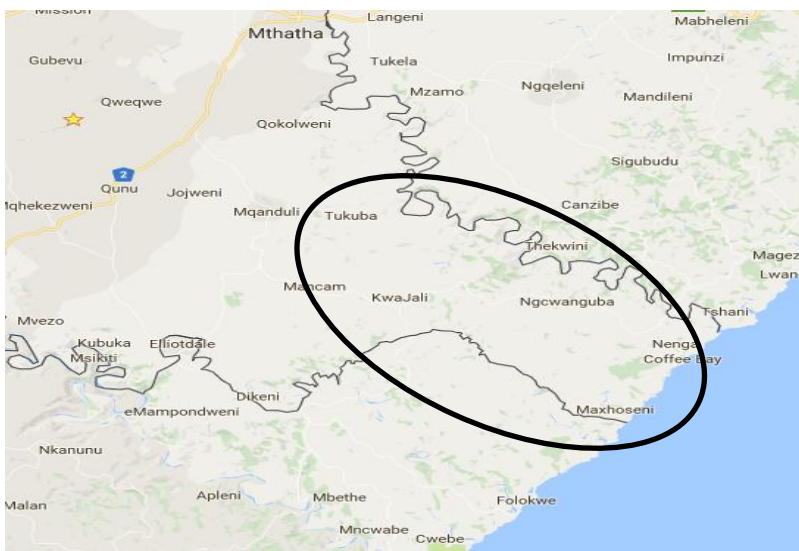


Figure 4-1 Map of rural participants' distribution within KSD municipal borders.

Figures 4-2 and 4-3 illustrates the urban participants' distribution in DuNoon, Khayelitsha and Delft.

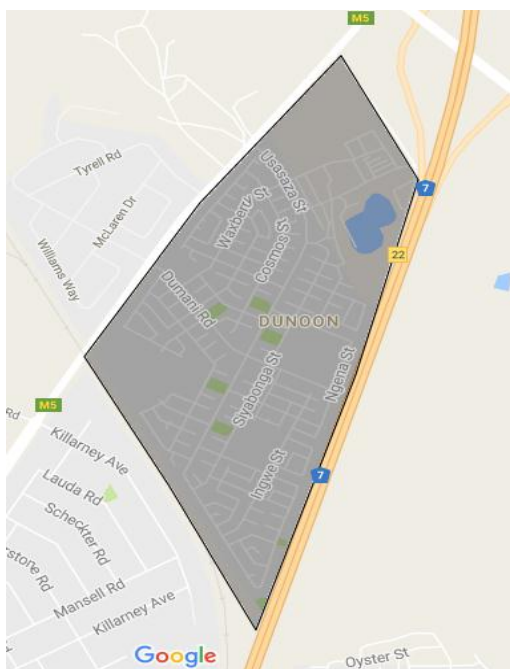


Figure 4-2 Urban participants' distribution in DuNoon



Figure 4-3 Urban participants' distribution Khayelitsha and Delft

In table 4-1 information regarding the participants' demographic, stroke related, health (comorbidity) and marital status are summarised for both settings.

Table 4-1 Study participants

Age and stroke-related factors		Rural Setting (n=11)	Urban Setting (n=9)
Age of participants in years (Median, Range)		42 (28-72)	56 (31-65)
Time since stroke in years (Median, Range)		5 (1-7)	3 (1-6)
Age of participants at stroke incident in years (Median, Range)		36 (23-69)	51 (28-60)
Time living in study setting in years (Median, Range)		26 (2-72)	15 (3-20)
Co-Morbidities			
None		18.2% (n=2)	11.1% (n=1)
HPT		27.3% (n=3)	55.6% (n=5)
HIV		45.5% (n=5)	0.0% (n=0)
More than one co-morbidity including HIV		9.1% (n=1)	22.2% (n=2)
More than one co-morbidity excluding HIV		0.0% (n=0)	11.1% (n=1)
Marital Status			
Single N (%)		6 (54.5%)	4 (44.4%)
Median age in years (Range)		29.5 (24-57)	50.5 (31-65)
Married N (%)		4 (36.4%)	3 (33.3%)
Median age in years (Range)		64.0 (56-72)	56.0 (56-57)
Divorce / Widowed N (%)		1 (9.1%)	2 (22.2%)
Median age in years (Range)		42.0 (36-52)	44.0 (36-52)

As illustrated, the median age in years at time of stroke was younger for the rural participants compared to the urban.

HIV (54.5%) was the highest self-reported co-morbidity among the rural participants. The urban participants had a higher prevalence of hypertension (55.6%) compared with rural counterparts. Participants in both the rural and urban settings stated that they took medication for all their self-reported illnesses.

In the rural setting 54.5% of the participants were single with a median age of 29.5 years (24-57) compared to 44.4% single participants in the urban area with a median age of 50.5 years (31-65).

All participants reported receiving a government grant, which was either a disability grant or old age pension, depending on their age. In South Africa, people who have previously received disability grants automatically receive a government old age pension when they turn 60. The amount payable for a government funded pension is equal to the disability grant.

4.3 Environmental differences between rural and urban study sites

This section describes the differences in contextual factors relating to the rural and urban settings. Factors reported include the physical and social characteristics of each environment. Data in this section were gathered using the D&E questionnaire and observations made by the researcher during data collection.

4.3.1 Products and technology

In this section the products and assistive devices used for indoor and outdoor mobility are presented. This section distinguishes between assistive devices issued to participants by healthcare professionals, those actually in use, and any further devices for which these participants expressed a need during the study period. The stacked bar graph in figure 4-4 summarises these results.

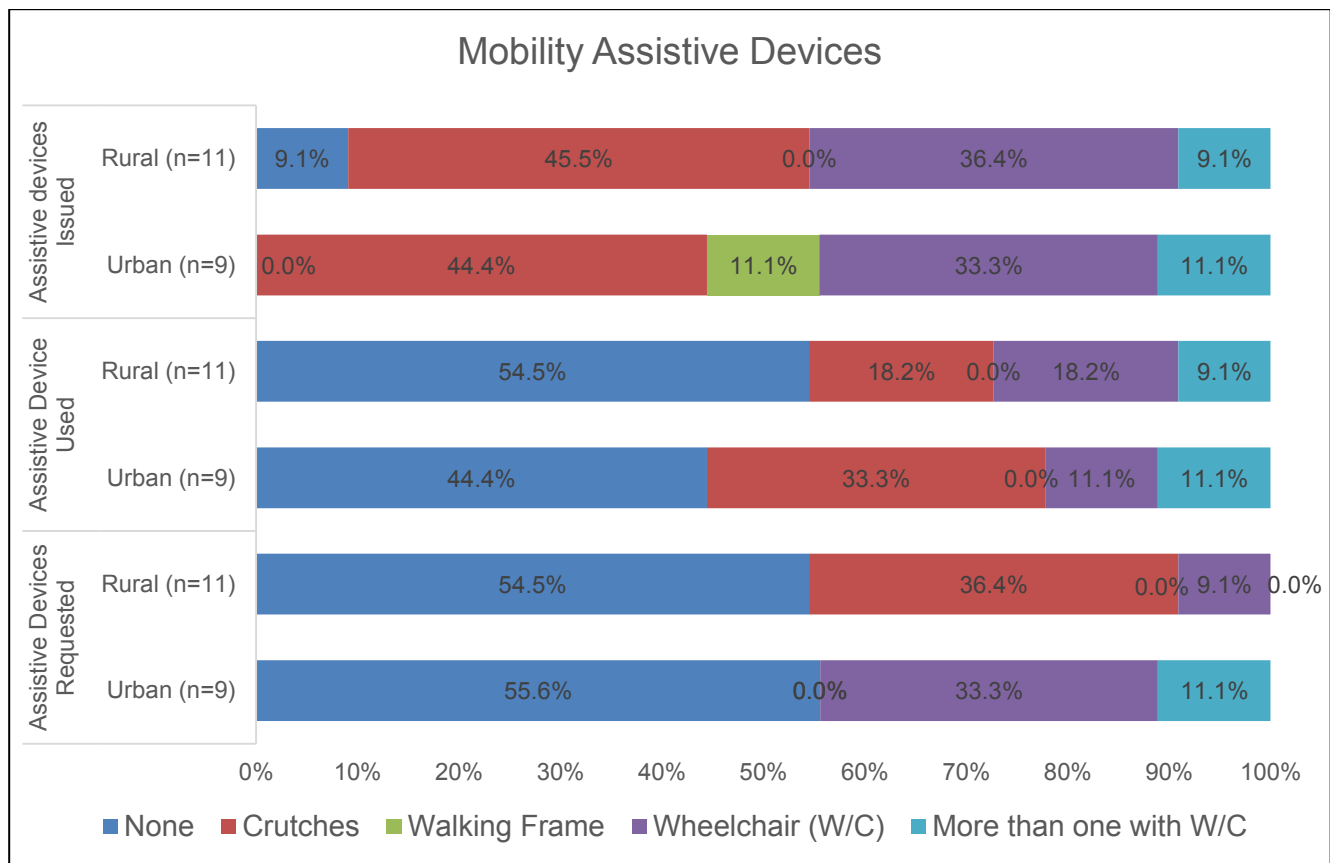


Figure 4-4 Mobility assistive devices of rural and urban participants

The majority of rural and urban participants received either crutches or a wheelchair. There were two rural participants and one urban participant who received more than one assistive device, such as a crutch and wheelchair.

Half of the rural participants reported that they did not use any assistive devices that were issued to them, nor did they need any other assistive devices. A third of the rural participants however expressed a need for new crutches.

A third of the urban participants (33.3%) expressed a need for a new wheelchair compared to only one rural participant (9.1%).

4.3.2 Support and relationships

This section describes social structures that are available to provide support to the participants. The stacked bar graph in figure 4-5 illustrates the different types of caregivers assisting the participants.

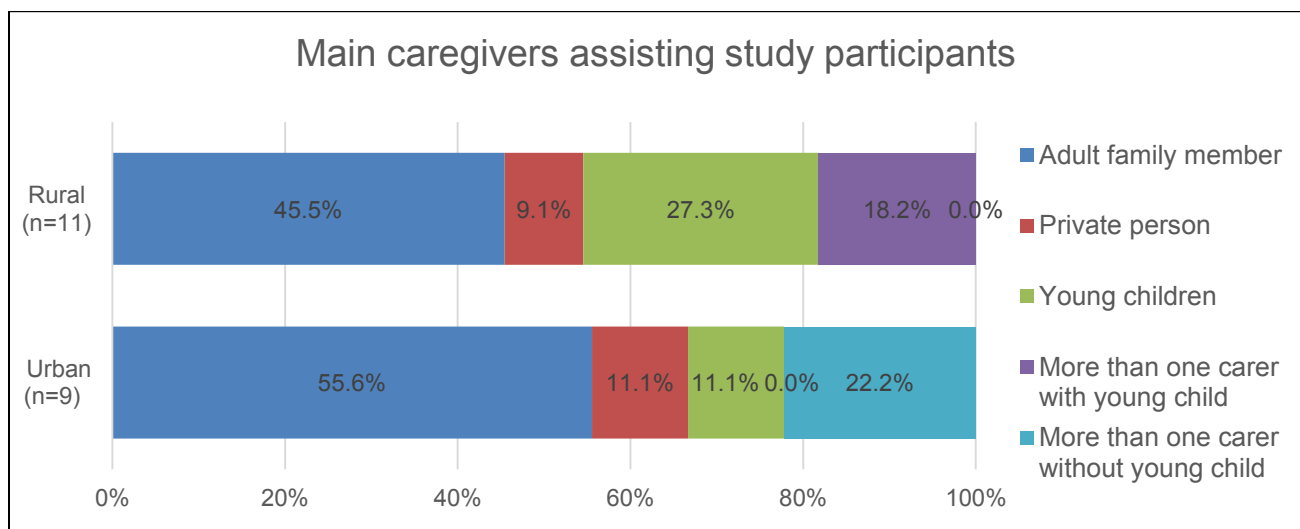


Figure 4-5 Sources of care for stroke participants in rural and urban settings

Over half of the urban participants (55.6%) and 45.5% of rural participants were cared for by adult family members. A much higher percentage of rural participants (45.5%) compared to their urban counterparts (11.1%) were cared for by children under the age of 18 years. Only one rural and two urban participants had to pay private people to assist them.

4.3.3 Natural environment and human made changes

All the rural participants reported that the terrain around their dwellings and community consisted of grass with narrow pathways. As observed by the researcher during data collection, these pathways were foot paths usually created by animals on grass surfaces. Figure 4-6 illustrates the natural environment in the rural setting,



Figure 4-6 Woman walking on narrow pathways between grass in rural setting.

A large percentage of urban participants reported more developed terrain around their homes and communities, consisting of concrete, bricks, or tar (44.4%). Sandy areas and narrow passages were described around the dwellings in informal settlements (33.3%). As observed during data collection, these narrow passages are prominent in informal settlements, where dwellings are densely crammed into small spaces.

4.3.4 Services and Systems

In this section the type of dwellings and access to amenities in rural and urban settings are presented, such as sanitation and cooking fuel. The transportation and healthcare services and systems available in rural and urban settings are also reported here. Data in this section, for these items, were drawn from D&E questionnaire and observation during data collection.

4.3.4.1 Housing, electricity and sanitation

Most rural participants lived in traditional huts (90.9%), compared to urban participants who lived in brick homes (44.4%) or informal dwellings (55.6%) in informal settlements. A high percentage of rural (90.9%) and urban (88.9%) participants reported that they had access to electricity for lighting.

Figure 4-7 illustrates the different water sources used in rural and urban settings

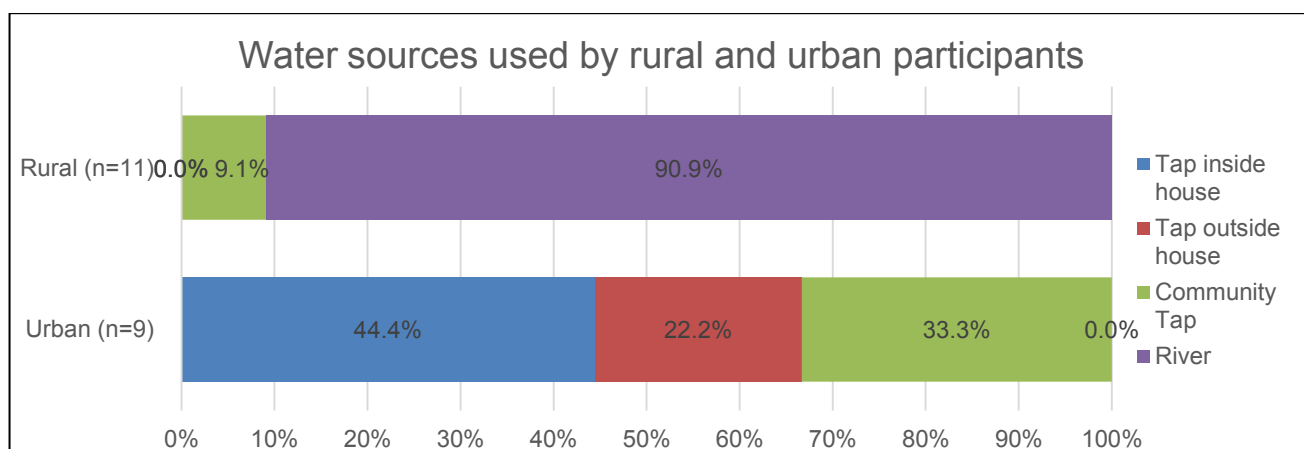


Figure 4-7 Water sources used by study participants

As illustrated in figure 4-6, 90.9% of the rural participants used rivers as a source of water. A large percentage of urban participants had access to piped water inside their dwellings (44.4%).

Different types of toilet amenities are in use by participants in the rural and urban settings. The stacked bar graph in figure 4-8 illustrates the toilet amenities used by study participants.

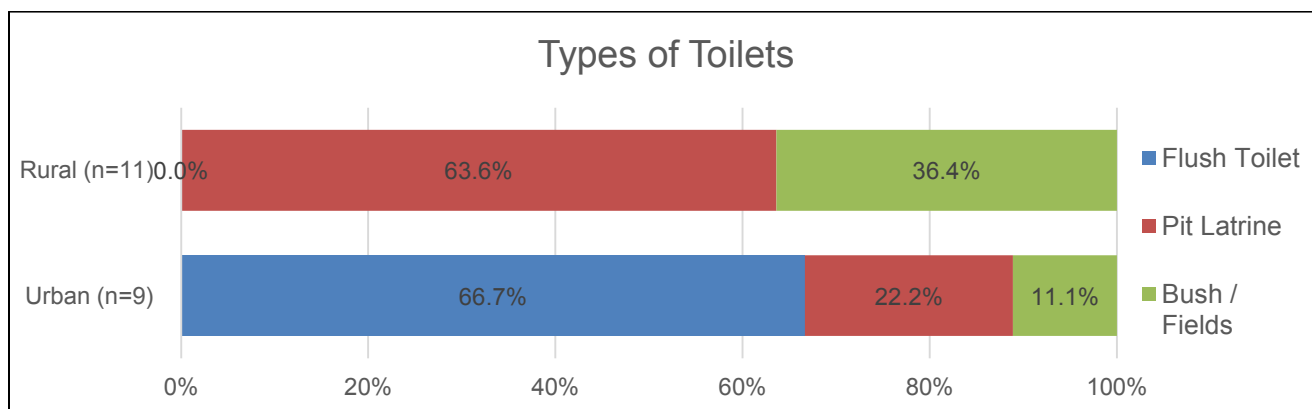


Figure 4-8 The different types of toilets used by participants in rural and urban settings

A large majority of rural participants (63.6%) reported that they made use of pit latrines (long drop toilets) while a third of the rural participants (36.4%) went to the open fields or bush for toileting. In contrast, two-thirds of the urban participants had access to flush toilets.

The stacked bar graph in figure 4-9 illustrates the location of toilet in relation to rural and urban participants' dwellings

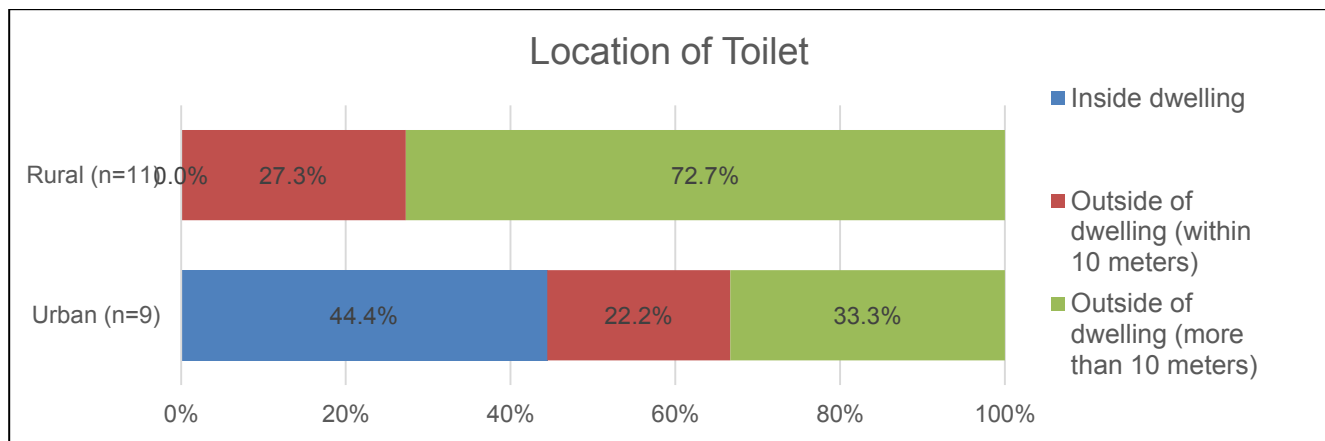


Figure 4-9 The location of toilet in relation to study participants' dwellings

The location of the toilets for 72.7% of the rural participants and 33.3% of the urban participants was further than 10 meters from their homes.

4.3.4.2 Cooking fuel

In this section the different types of fuel used for cooking purposes in rural and urban settings are highlighted. From the researcher's observations, in the rural setting, wood is used to make an outside fire to cook on. In both the rural and urban setting paraffin is bought which is used in a small portable open flame stove used inside the home for cooking purposes. The stacked bar graph in figure 4-10 illustrates the different types of cooking fuel used by rural and urban participants.

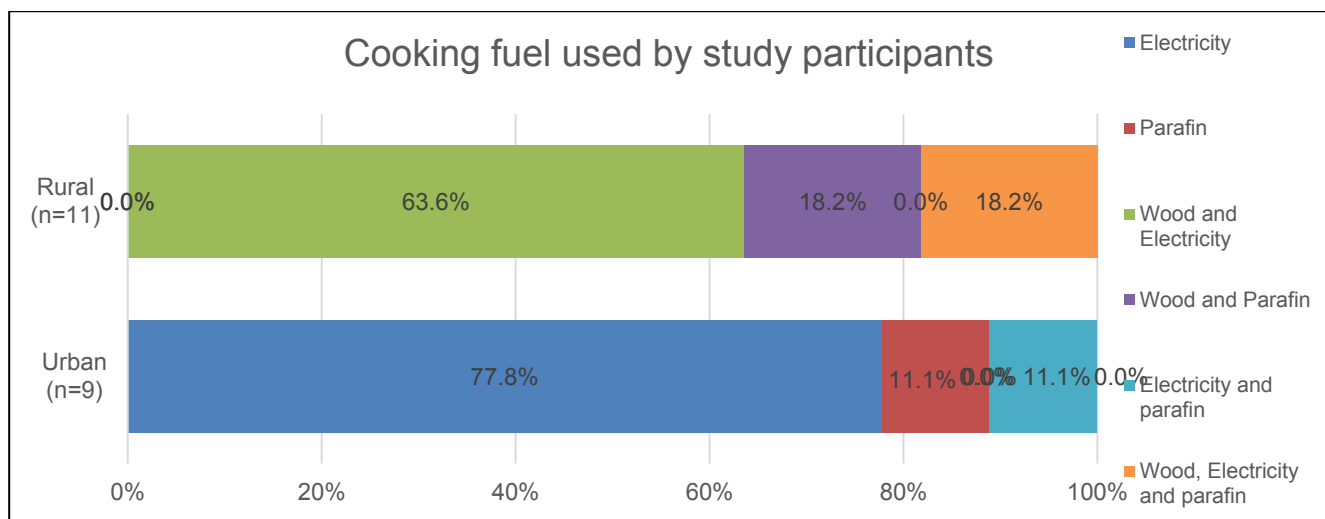


Figure 4-10 The cooking fuels used by study participants

Wood, used to make a cooking fire, was used by all rural participants in combination with other cooking fuels, whereas 99.1% of urban participants used electricity either exclusively or in combination with other fuels for cooking.

4.3.4.3 Transport

Accessing and using transportation is essential for re-integration into community living and participation in life roles. In this section, we discuss the different transportation services used by rural and urban participants both before and after the stroke.

Before experiencing the stroke, 90.1% of participants in the rural area and all (100%) in the urban setting used taxis, either exclusively or in combination with other public transport services. One participant in the rural setting used to walk exclusively as means of transport before the stroke. Taxis in this study refer to minibuses which travel set routes, and offer the most affordable mode of transport in South Africa. These non-metered taxis are privately owned and their business is governed by taxi associations. In the rural setting, taxis may be minibuses or in more remote locations single-cab pick-up trucks, as roads in these areas are less accessible to normal modes of transportation.

After experiencing the stroke, 72.7% of rural and 88.9% of urban participants reported having access to transport. The different types of transportation services used by participants after the stroke is summarised in the stacked bar graph figure 4-11.

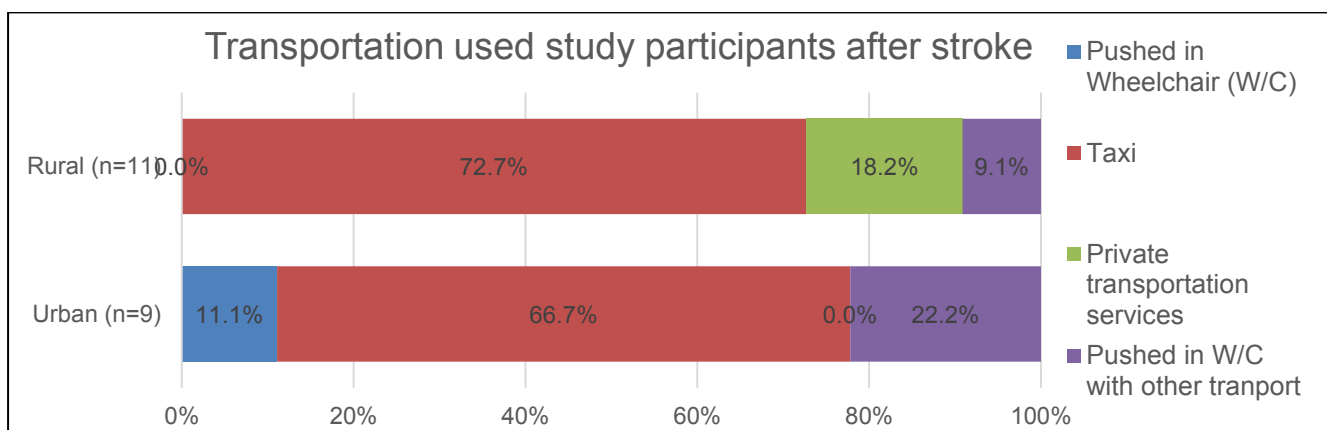


Figure 4-11 Transportation services used by study participants after the stroke.

The majority of rural and urban participants still used taxis exclusively as a means of transport after the stroke. There was an increase in the need for private transport services in rural areas. Private transportation services consisted of private vehicles owned by other community

members, who would pick participants up at their homes and take them to their destinations. Participants in both settings were dependant on others to push them in a wheelchair to reach their transport.

4.3.4.4 Utilisation of healthcare services

The majority of rural (90.9%) and urban (88.9%) participants visited local clinics on a regular basis. The stacked bar graph in figure 4-12 illustrates which healthcare professionals the women with stroke in rural and urban settings saw regularly at these healthcare facilities.

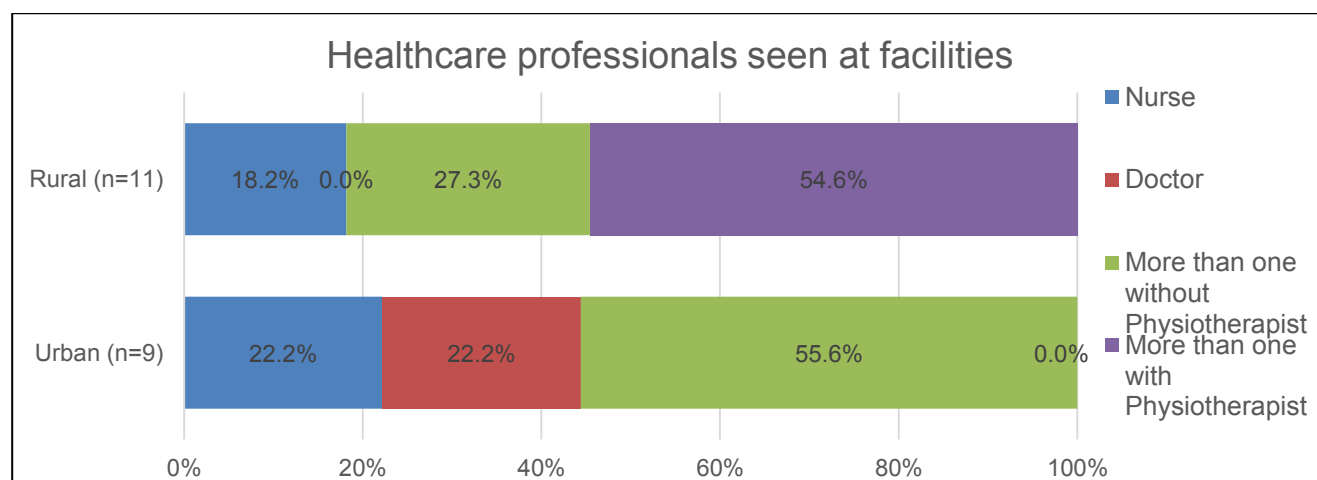


Figure 4-12 Healthcare professionals seen at their healthcare facility by study participants

All the rural participants and 77.8% of urban participants were treated by nurses at healthcare facilities on a regular basis. In the rural area 54.5% of the participants were seen by a physiotherapist in combination with either nurses or doctors. None of the urban participants reported being treated by a physiotherapist or other rehabilitation therapist.

Within this section environmental differences between the rural and urban settings were discussed, categorised according to the domains of the International classification of functioning, disability and health (ICF). The largest disparities between rural and urban settings were reported in relation to the natural environment and services.

4.4 Activities in the household and community of rural and urban participants

In this section, the community activities in which the women in the study participated both before and after the stroke are reported, as gathered using the D&E questionnaire. Qualitative data gathered on this topic during the SSI is further described in section 4.8.

A large percentage of rural (81.8%) and urban (88.9%) participants reported that they could move around in their home.

A larger percentage of rural participants reported they could mobilise in their community (72.7%), compared with only 44.4% of their urban counterparts.

The stack area graph in figure 4-13 compares the number of activities in which women participated before and after the stroke in rural and urban settings, as reported in the D&E questionnaire.

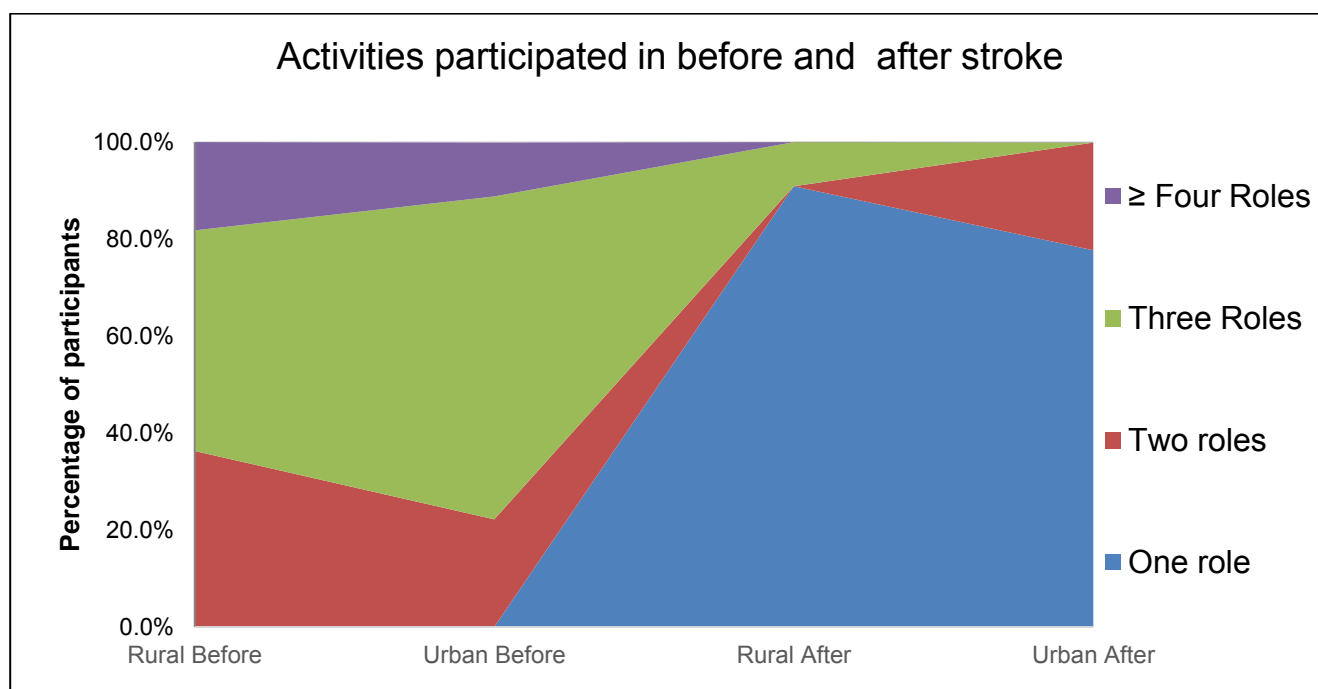


Figure 4-13 Number of activities participated in before and after the stroke

Figure 4-13 illustrates a decrease in number of community activities engaged in by the study participants after the stroke. The participants' perceived participation restrictions will be further discussed in section 4.8. Activities participated in before the stroke included shopping, working, and attending religious activities and community meetings.

Looking after children was a responsibility highlighted by an overwhelming majority of participants in both rural (90.9%) and urban (100.0%) settings. The mean number of children looked after by rural participants were four (1-4) compared to three (0-6) in an urban environment. Few participants had to look after adult family members in either rural (9.1%) or urban (11.1%) settings.

In figure 4-14 the ages of the youngest children cared for by participants in rural and urban setting are illustrated.

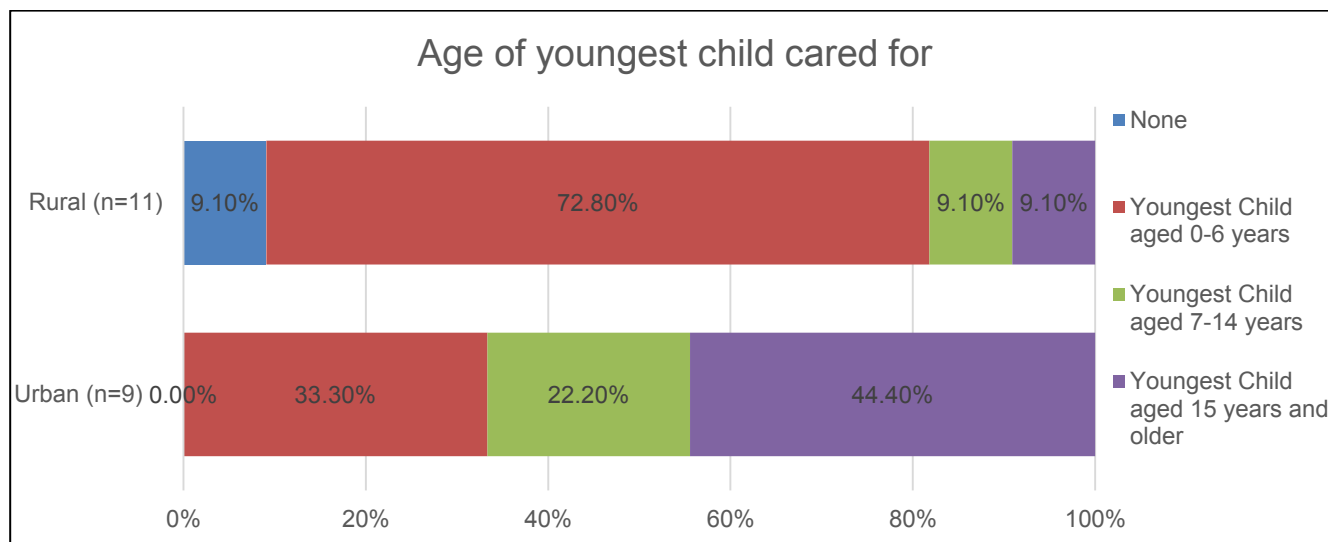


Figure 4-14 Ages of the youngest children cared for by the participants in both settings.

Activities performed in the household are discussed in-depth with the presentation of the qualitative data in section 4.8.

4.5 Functional ability in activities of daily living of rural and urban participants

The Barthel Index (BI) was used to describe the functional abilities of all participants in activities of daily living. The total median Barthel Index score for rural participants of 80 (40-95) was the same as the median score for urban participants at 80 (10-100). In figure 4-15 the median scores for rural and urban participants in each Barthel Index activity are illustrated.

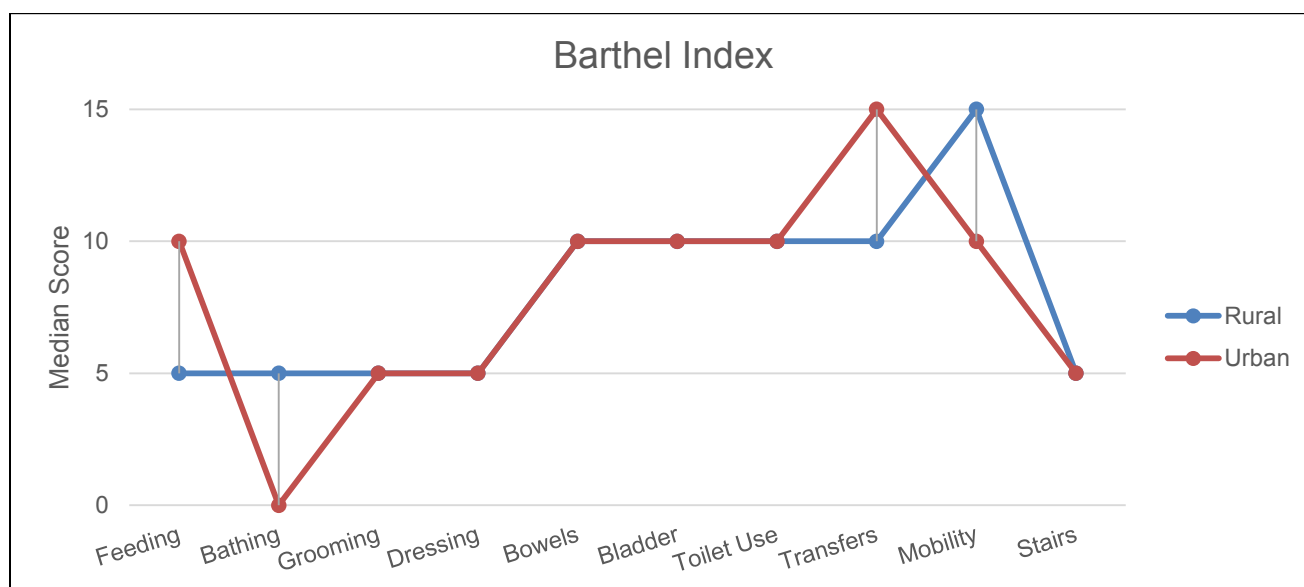


Figure 4-15 Differences in rural and urban median scores for each of the Barthel Index activities.

As illustrated in figure 4-15 there are minor differences in the median scores for feeding, bathing, transfers and mobility for the women in the two settings, however these were not substantial.

In the rural setting 81.8% participants needed assistance with feeding, while 66.7% of the urban participants were independent with feeding themselves. This included basic meal preparation activities such as cutting food or smearing butter.

Almost two thirds of the rural participants (63.6%) needed assistance with transfers compared to only 33.3% of the urban participants. In the rural setting 63.6% of the participants were independent with mobility over an even surface, compared to only 44.4% of urban participants.

In summary, while the total BI scores for rural and urban participants were the same, there were differences in the median scores of some of the individual activities assessed. Rural participants scored higher in bathing and mobility, whereas the urban participants scored higher in feeding and transfers. The sample was however too small to accurately detect a statistically significant difference.

4.6 Self-reporting of health-related quality of life (HRQoL) of rural and urban participants

In this section the self-reported HRQoL scores collected using the EQ-5D are presented. The instrument's visual analogue scale describes participants' HRQoL on a scale of 0 to 100. Information is also reported from the EQ-5D's health state dimensions, which include the participants' ability to mobilise, performance in self-care activities and usual activities, problems with pain, and anxiety and depression.

The 20cm VAS represents the overall perception of one's quality of life after stroke. The median EQ-5D VAS score was 50 (30-80) for the rural and 55 (20-90) for the urban participants respectively. This illustrates that the two groups were very similar in their overall experience of their quality of life after stroke but the sample size was too small to detect any significant differences.

The ordinal data obtained from the EQ-5D health state dimensions was represented numerically, from 1 for "no problem" to 5 for "extreme problems". The median results of EQ-5D dimensions for rural and urban participants are presented as the line graph in figure 4-16 below. A pivot table with the percentages of the different responses within each dimension is attached as Appendix 9.

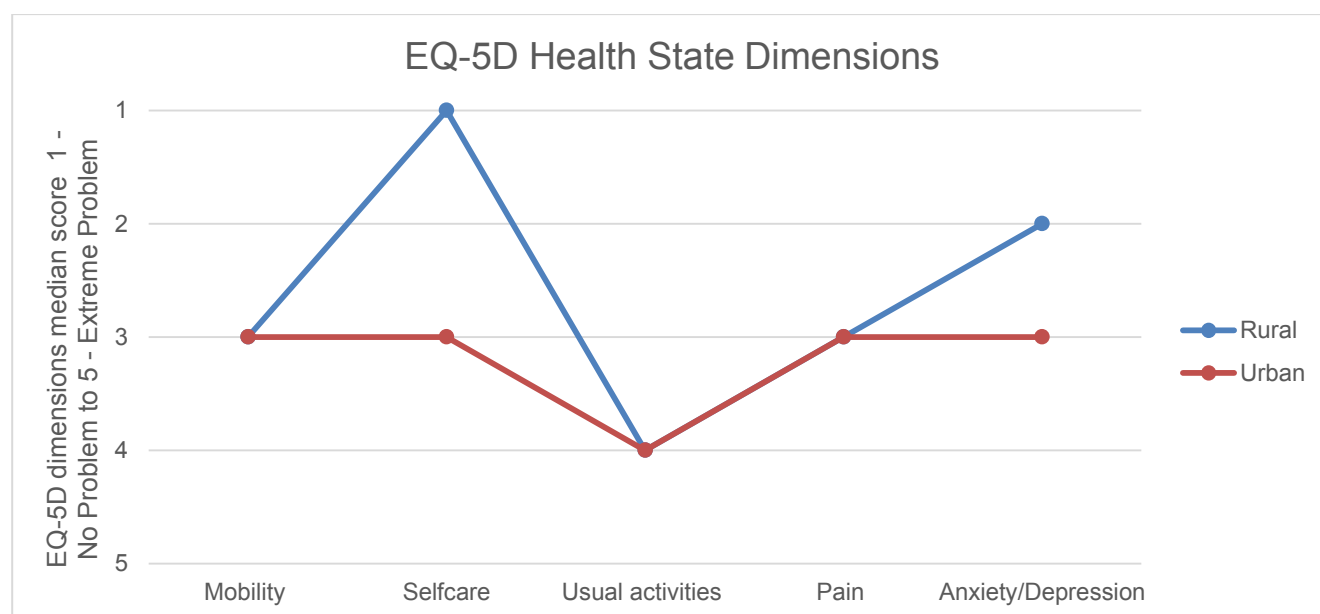


Figure 4-16 Median scores for EQ-5D health state dimensions

In figure 4-16, differences in the median scores for the dimensions of self-care and anxiety and depression are seen. In both dimensions, the rural participants reported that they experienced less problems compared to their urban counterparts.

Half of the rural sample (54.5%) reported no problems with self-care activities, however half of the urban participants reported that they experienced moderate (22.2%) to severe (33.3%) problems with self-care.

Almost two thirds of rural participants reported that they have no (18.2%) to slight (45.5%) problems with anxiety and depression, however half of the urban participants reported that they experienced slight (22.2%) to moderate (33.3%) problems with anxiety and depression.

In summary, despite the urban participants having a slightly higher HRQoL VAS score, the rural participants reported less problems in the HRQoL state dimensions of self-care and anxiety/depression.

4.6.1 Correlation between Barthel Index and EQ-5D

A correlation co-efficient analysis was conducted between the total Barthel Index and HRQoL EQ-5D VAS score for the whole study population. No significant correlation was detected ($r=0.33$, $p=0.1502$).

There was also no correlation between the rural total Barthel Index and EQ-5D VAS ($r= -0.0360$, $p=0.9163$) or urban total Barthel Index and EQ-5D VAS ($r=0.5758$, $p=0.1047$).

It must be highlighted that due to the small sample size in this study the statistical analysis and interpretation thereof is limited.

4.7 The life roles, role responsibilities, activities and task requirements of rural and urban participants

The SSI was conducted to gain an in-depth understanding of the participants' perceived participation restrictions, which for the purposes of this study included the activity and task requirements of fulfilling their life roles within their own context.

In this section, the life roles and role expectations expressed by the participants in the SSI are described. The activity requirements to fulfil these life roles, and how these are shaped by the environment shape, are described and compared across the rural and urban settings. The emerging themes relating to these participants' emotional and personal perceptions of life after stroke are described.

SSI were conducted with all the rural (n=11) and urban (n=9) participants. The first interview however was excluded from analysis, as the starting question did not elicit an optimal response from the participant (as discussed in section 3.8.4), and the voice recording was too soft to be successfully transcribed. Ten rural and nine urban participants' interviews were successfully recorded, transcribed, translated and analysed.

Life roles are derived from behavioural expectations and responsibilities from the status which a person attains (McKenna, Liddle, Brown, Lee et al., 2009). The study participants' roles, as emerging from the SSI, were constructed from the activities and task responsibilities perceived by the women to be personal and social expectations, relating to their status as Xhosa women.

The roles derived from the status of being a Xhosa woman emerged as discussed in section 3.10.2. The quotations below from participants 5 and 6 in rural setting and participant 15 in urban setting are examples of women referring to these expectations placed on Xhosa women.

Participant 5 (rural): "When you are a woman you go fetch the wood, you have to smear the walls and you do all the house chores inside the house." (5:32)

Participant 15: "[The responsibilities of a woman are] to clean the house, make sure that there is food in the house, do the laundry for the children and cook for them. Also, to bath those who were going to school." (15:48)

Participant 6 (rural): "Those are the things that I really enjoyed doing as I am a traditional woman from the village." (6:5)

In the SSI women in both settings expressed the same life roles that were expected from Xhosa women. The participants described their life roles as self-care, provider, caregiver and community member.

The self-care role included responsibilities to care for themselves by performing activities of daily living, accessing transportation and taking care of their health.

The provider role encompassed role responsibilities of providing shelter, home maintenance, acquisition of goods for the household and financial support.

The caregiver role included role responsibilities such as preparing meals, completing house chores and looking after children.

The community member role included role responsibilities for participation in social groups, community events and religious activities.

The hierarchy graph in figure 4- 1 illustrates the different roles of a Xhosa woman as described above. In figure 4-17, these roles are presented together with their role responsibilities, as discussed by study participants in both settings.

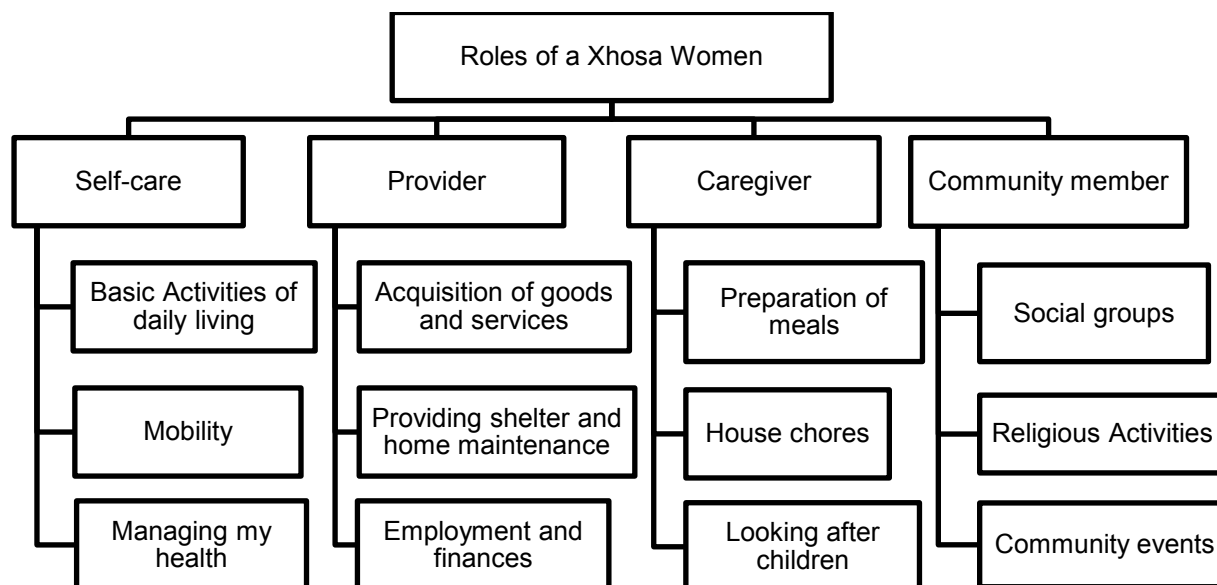


Figure 4-17 the different life roles and role responsibilities of study participants.

4.7.1 Self-care

Self-care activities are often viewed as basic requirements for other roles, but participants in both settings expressed personal expectations and a desire to be able to care for themselves, showing that these activities were valued for their own sake. Both rural and urban women with stroke reported difficulty with self-care activities such as bathing, grooming, dressing, toileting and taking care of their health by going to the clinic for check-ups. In the hierarchy graph of figure 4-18 the self-care role responsibilities, activity and task requirements are summarised

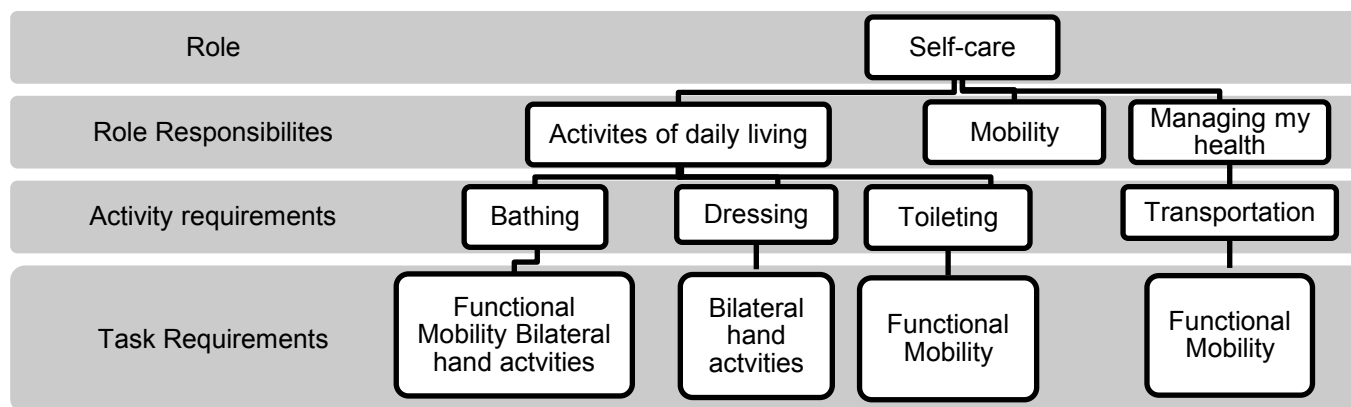


Figure 4-18 Responsibilities, activity and task requirements for the self-care role

4.7.1.1 Activities of daily living

i. Bathing

All participants were asked about the task requirements of bathing and their ability to perform them. Three rural and six urban participants expressed difficulty in participating in self-care activities such as bathing. Participants in neither setting made use of a shower or bathtub, but had to wash themselves using a washbasin filled with water. Both rural and urban participants indicated that they struggled to boil water, carry it and pour it into a small tub or basin for bathing. Participants who had access to electricity would use electrical appliances such as kettle or stove to boil water. Participants who did not have access to electricity used a paraffin or gas stove, while some rural participants boiled water on the fire.

Participant 12 (rural): “No someone needs to wash me...[before the stroke] I was able to cook water. I will pour water in the basin and then I will bath. Even if it’s a big washing basin (bigger basin) I will get in and I will bath.” (12:88)

ii. Dressing and grooming

Participants in both settings struggled with dressing and smearing themselves with lotion or Vaseline after bathing.

Participant 4: “I can’t undress myself, I need to ask someone to help me.” (4:13)

Participants in both settings described how their impaired body function restricted their independence in self-care.

Participant 19: “Before I would wash myself. But now I can’t because this side is not working.” (19:21)

iii. Toileting

All the rural participants and four of the urban women reported having to mobilise outside of the home to use the toilet. Women with stroke in both settings had to either mobilise to an outdoor pit latrine, or to designated areas in fields or forest (in rural areas) to relieve themselves.

Participant 5 (rural): “[Before the stroke] I will go to the fields; I will kneel and relieve myself.” (5:177)

Participant 12: I don’t have one [toilet]. We all go to the forest. I will limp and go there. (12:288)

Three rural and one urban participant needed assistance with going to the toilet outside their homes. The participants expressed problems with mobilising over rough terrain in their location.

Participant 10 (rural): “I wish I could fly to the toilet, there is too much grass and my leg struggles to try and move.” (10:233)

Participant 19 (urban): “The challenge is when it’s raining there is a lot of water which makes it difficult to cross to that side.” (19:199)

4.7.1.2 Mobility

Mobility is essential to complete basic tasks and activities. Self-care activities such as bathing and toileting required participants to be able to mobilise. Restrictions related to mobility were mentioned as underlying reasons why participants were not able to complete some self-care activities, such as bathing which included fetching water and carrying it to the washing basin.

Mobility was also essential for safety. Women with stroke in the urban setting expressed a fear that if something happened and they would need to flee, they would be unable to do so.

Participant 18 (urban): “Even if there was death, I will die in this bed, because I can’t even move from here. Even if there would be an incident that I would have to run away, I can’t. I will just die here.” (18:195)

Another participant described what she was especially afraid of in this regard:

Participant 17 (urban): “The other thing is that I live in the informal settlement as there is the problem of fire.” (17:17)

Although some of the participants in both settings expressed that they could walk outside their home, others were limited in their capacities. Participants who could mobilise outside their

homes expressed a fear of falling or losing their balance, and some preferred to crawl on the ground to ensure their safety.

Interviewer: "Where is the toilet here?"

Participant 11 (rural): "No I don't go there. I go that side [indicating to edge of household towards forest, steep downhill]... I will crawl. Sometimes I will feel pains here [indicates knees]." (11:378)

Participant 4 (rural): "Sometimes I crawl on the pathways because the fences are too far [to hold on to]." (4:138)

4.7.1.3 Clinic visits

Participants in both settings had to attend clinics for medical check-ups and to collect their medication, as part of looking after their own health. Participants who lived close to the healthcare facilities would walk there, but only two rural participants walked to the clinics.

Participant 12 (rural): "I do walk to the hospital on my own. I do not take a car... I will limp until I get there...I walk with my feet, I do not take a car. (12:260)

Most participants made use of transportation to get to clinics, as described in 4.3.4.3.

Women in rural areas would have to walk to the nearest main road and wait for a taxi to come past and pick them up. In more remote areas taxi are scarce and inconsistent.

Participant 4 (rural): "I wait for a long time. I will sit... Sometimes they are very scarce or they are not available at all." (4:105)

In urban areas women, would have to walk either to a main road to wait for a taxi to pass, or to a taxi rank to access transport. Walking to access transport was often difficult as participants struggled to mobilise long distances.

After the stroke, some participants in both settings were unable to walk to access transport and would have to be pushed in a wheelchair. However, participant 15 reported that the wheelchair was inappropriate for the terrain over which it was used.

Participant 15 (urban): "We walk on the tar, but in front of the house it is sandy. I would walk slowly supported by someone out of the gate until I get to the tar road and get into a wheelchair...the wheelchair can't go on the sand. The one I had got broken here in the sand." (15:93)

Participant 15 highlighted how not only the terrain and her physical environment created barriers, but how an inappropriate assistive device such as this wheelchair further restricted her mobility and participation.

Women in both areas expressed that they struggled to transfer into the taxi and often requested to sit in the front as it was an easier transfer. Participant 15 even preferred being pushed in a wheelchair as she felt uncomfortable with the difficult transfers in and out of the taxis.

Participant 15 (urban): “I can’t balance with this leg as the taxi is a bit high. I will have to let people struggle to get me in as I am heavy [overweight]. So I prefer using a wheelchair.” (15:127)

Two urban participants reported that they were pushed in wheelchairs to the clinic. Despite the wheelchairs not being suited for rough or sandy terrain, once they reached the tarred road or sidewalks family members could push them with ease.

The combination of climate and terrain also affected participants’ mobility and access to transport. If it was raining it was difficult to access transport as the women would struggle to mobilise over the wet surfaces. In the rural setting transport was limited if it rained as roads became inaccessible.

4.7.1.4 Environmental factors influencing the self-care role

Lack of basic amenities turned activities such as bathing and toileting into far more complex undertakings, with additional tasks not necessary where hot running water and sanitation are available inside the home.

The lack of access to fully equipped bathrooms made it necessary for participants in both settings to complete extra tasks such as boiling water, carrying it to the basin and washing themselves from it. Availability of cooking fuel could also affect task requirements and the time taken. Participants who had access to electricity could use a kettle which was fairly quick, but others had to boil water on paraffin stoves or on an open fire, which was far more time consuming.

The lack of basic sanitation amenities inside the home made it necessary for participants to mobilise outside their home to access toilets. Some of the toilet facilities were far away from the home, and some rural and urban participants preferred going to relieve themselves in the fields. This also required them to be able to squat on the ground.

Although few women with stroke were unable to access transport at all, they still expressed difficulty in reaching taxi pick-up points, especially in inclement weather. Mobility over rough terrain and inappropriate wheelchairs increased the barriers to community mobility.

4.7.1.5 Personal experiences of fulfilling the self-care role after a stroke

Rural and urban participants expressed the need for external support to complete self-care activities. Participants required assistance from either adult family members or children to assist with bathing. In addition to family support, some urban participants also had assistance from home-based carers who conducted home visits in their community which the rural participants did not report.

Participant 15 (urban): "There is also one that comes and baths me. I told her that I haven't had a proper bath as I am assisted by the children and then she will bath me." (15:139)

Participants in both settings had emotional responses of frustration and sadness relating to their dependence on others. Participants expressed frustration relating to impairment of body function, such as the inability to use or move their affected upper limb, as well as pain.

Participant 4 (rural): "It's difficult because this hand that use[d] to help is the one that is not working and [not] allowing me to do these things." (4:53)

Participants expressed they also did not see themselves improving.

Participant 9 (rural): "I do exercises, but I cannot see it working. They will give exercises, but I don't see it's work." (9:173)

After the stroke, participants in rural and urban environments expressed frustration, sadness and fear with their limited mobility after the stroke. These emotional responses related to depression and loss of hope. The loss of hope was often associated with their dependence on others in basic activities of daily living together with seeing limited improvement. This gave them very little hope of returning to previous roles and valued activities.

Participant 14 (urban): "I can't say anything now, because I am just sitting here doing nothing. There is nothing that I do." (14:9)

Participant 10 (rural): "As you can see right now I can feel that my body is giving up as my heart is always sad." (10:58)

Despite the participants' loss of hope with their physical abilities, they still took pride in self-care activities and had a sense of self-worth.

Interviewer: "Oh you still like looking smart?"

Participant 6 (rural): "Sure thing. I haven't given up on my life." (6:46)

The participants showed determination to improve their abilities, but also strategized to make appropriate adaptations so they could complete activities independently.

Participant 16 (urban): "I end up able to dress myself... Because it is something I want to do." (16:33)

Participant 16 (urban): "No I don't buy shoes with shoe laces." (16:53)

The women who were independent in toileting inside and outside their homes showed the ability to strategise and make adaptations to fulfil their basic, but essential, toileting needs.

Participant 5 (rural): "I always have a stick to pull it [bedpan] closer. Then I can reach it and use it." (5:186)

Participant 19: "No I can go [to the toilet], but I need to wear something without a belt. It would need to be a track suit." (19:215)

This deep sense of self-worth gave many the drive and determination to strategise and work towards becoming more independent. As far as possible they would adapt to their impairments and implement strategies to overcome their impaired abilities.

Participant 6: "Yes, it will be until sunset and there will be no one. That is when I trained to wash myself and I realised I could wash my back. I was then able to bath myself." (6:256)

4.7.1.6 Summary

Women in both settings struggled with self-care activities such as bathing, dressing and grooming themselves, going to the toilet and accessing healthcare facilities. The activity requirements to fulfil the self-care role were influenced by available amenities inside the home such as bathroom and toilet facilities and hot running water. Restrictions in self-care and health management activities related to participants' restrictions in their body function, mobility indoors and outside, and accessing transport. Women with stroke in rural and urban settings reported that their fear, body impairments and terrain negatively affected their independent mobility. Participants were often assisted with basic self-care activities by adult family members or younger children. Urban participants had home-based care services available.

4.7.2 Provider

Participants in both settings lived permanently with other family members or children. The participants did not only have to complete instrumental activities of daily living such as preparing a meal and completing household chores such as laundry for themselves, but they had to provide these services for others. The participants in both settings had responsibilities to provide shelter, subsistence and financial support not only for their own survival, but for their household. The hierarchy graph in figure 4-19 summarises the different responsibilities included in the role of provider.

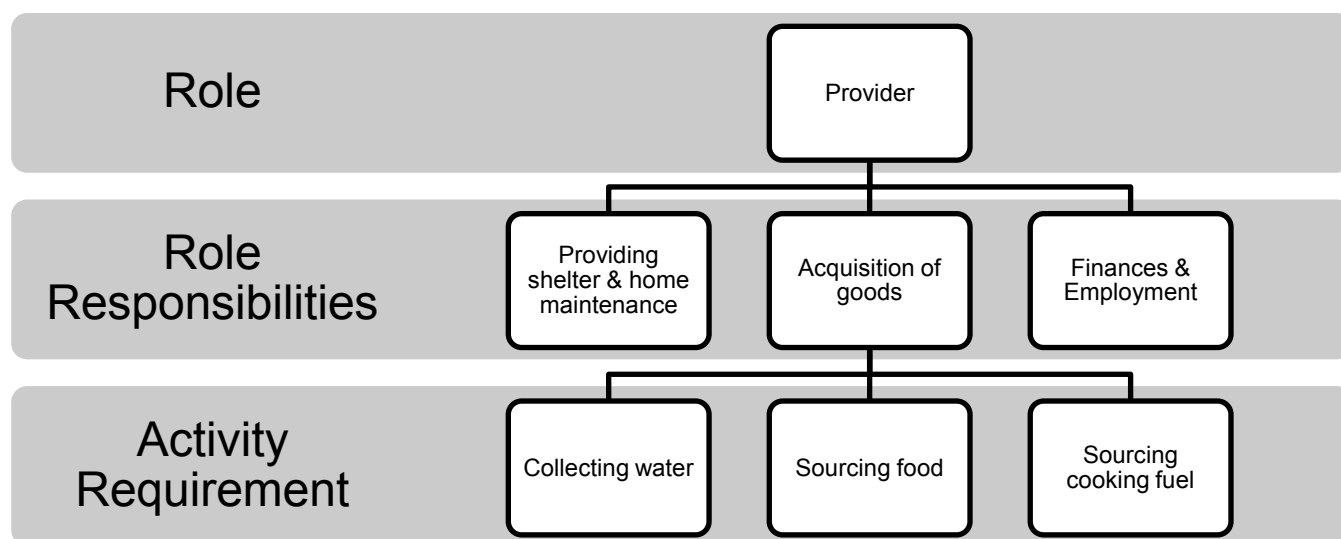


Figure 4-19 Provider role and role responsibilities

4.7.2.1 Providing shelter and home maintenance

In this section, the different activities relating to the role responsibility of providing shelter and maintaining dwellings in the rural and urban setting are discussed. In the hierarchy graph in figure 4-20 the role responsibilities of provider, relating to provide shelter and home maintenance, are illustrated with the associated activity and task requirements.

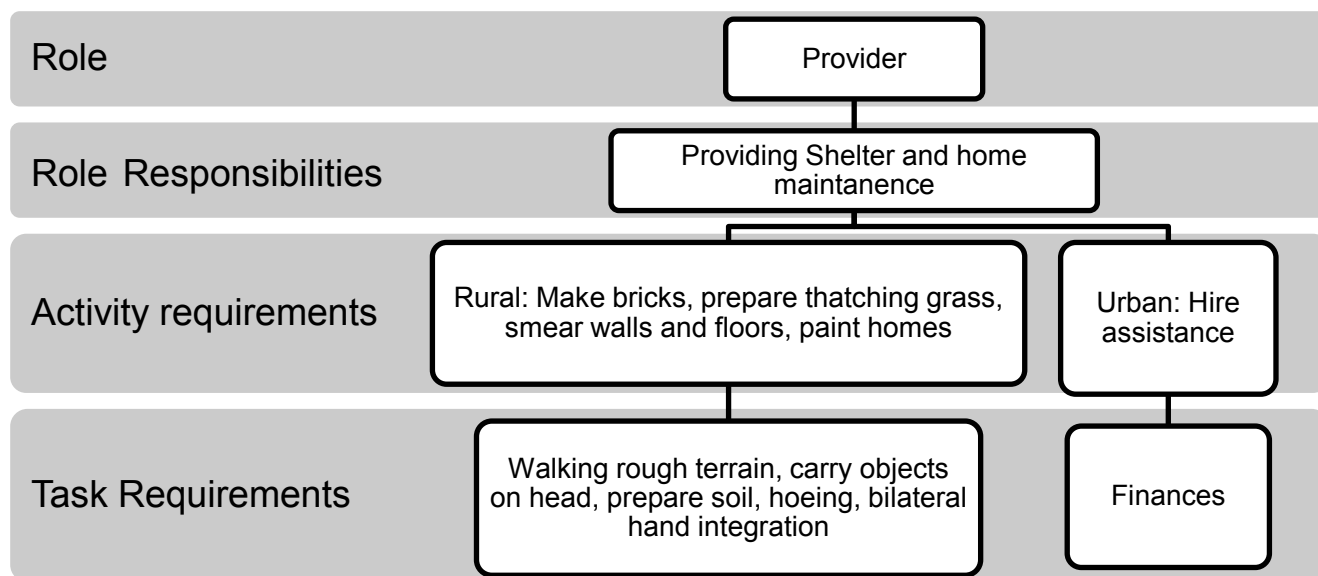


Figure 4-20 Provider role's responsibilities, activity and task requirements for providing shelter and home maintenance

In the rural setting the traditional dwellings were made from clay bricks and thatched roofs. The rural participants had more tasks associated with providing shelter and home maintenance compared to urban participants.

Urban participants lived in either Reconstruction and Development Program (RDP) houses built by government, or informal dwellings in informal settlements. The formal houses were either bought or rented, which meant that providing shelter in the urban area imposed a bigger financial burden on participants.

In the rural setting, the most labour intensive activities were the responsibility of the women. Rural participants described how they would assist in building their homes by making the clay bricks and preparing the grass used for thatching the roof.

iv. Making bricks

The rural women were responsible for making the clay bricks used to build the traditional dwellings. The clay brick walls and the floors were afterwards smeared with a soil mixture for protection and decoration. The bricks were made from a mixture of soil, water and either cow dung or cement, and were prepared outside the home.

Participant 10 (rural): "I use[d] to... make bricks [ukutena]. Interviewer: Did you do those things by yourself? Participant 10: I use[d] to do them on my own. I would also go out in the open field (isiza) and then dig with pickaxe (ipeki). I

*will bring the soil back and prepare it and I will call the bricklayer (ingcibi).”
(10:38)*



Figure 4-21 Xhosa women carrying object on head when making bricks

Women with in the rural setting also expressed that they were responsible for collecting and preparing the grass before the men would thatch the roof. The women would collect and cut the grass in the fields or next to rivers and then carry it on their heads back to their dwellings.

Participant 10 (rural): “I will go to the river you saw when you came and get it from there. And we will cross the river putting it on your heads and we will walk on that rough terrain up from the river and carry it to our homes.” (10:308)

The rural and urban participants expressed that they used to carry heavy objects over long distances by balancing them on their heads. This was not only a cultural way of doing it, but an efficient way of carry heavy objects over rough terrain, as the weight distribution would be more evenly spread through the spine.

v. Home maintenance

In the rural setting the traditional dwellings required frequent maintenance which, as with most manual labour activities, often fell on the Xhosa women in the household to complete. The role of home maintenance was particularly expected from young newlywed women.

Participant 11 (rural): I will do them (smearing the walls and floors) myself as I was a newlywed and still young. I had to do those things. (11:83)

Urban participants had less activities relating to home maintenance, as here the home maintenance activities and responsibilities fell on the men, or participants hired professional services to do repairs.

Participant 14(urban): "Ok, I would call someone and pay him to fix it for me... I will hire and I still do now." (14:58)

In the rural setting, women were responsible for maintaining the dwellings by smearing the walls and floors with a mixture of soil, cow dung and water. The walls were also smeared with paint mixture (*ikalika*) for decoration. Preparation of the soil mixture entailed walking to the river to fetch water, digging up soil and carrying it back, traditionally balanced on the participant's head.

Participant 5 (rural): "I will dig with the hoe and bring the soil closer to home and mix it with cow dung to turn it into mud. Then I will smear the walls." (5:85)

Participant 6 (rural): "There where the car is. You dig there and then carry it to right in front of the house. You also still need to fetch water from the river and put it on your head. Then you prepare the mud and start smearing the walls and floors. And then you prepare the lime and then smear it on the walls, but I can't. (ikalika)." (6:27)

Smearing the walls and floors was felt to be a meaningful activity for rural participants. They saw it as part of their role as a Xhosa woman, and they were trained to do it from a young age.

Participant 8 (rural): "Yes that (smearing the floors) was one of my favourite things to do even in my childhood. It is something I use to learn when I was a child until I reached my adulthood and became a woman. Those were one of the things we were learned. After learning how to maintain the hut you then learn how to cook, how to go to the forest." (8:35)

It was not only seen as a maintenance task, but also a means to decorate and make their home look beautiful. Caring for their homes gave them a sense of pride and self-worth. They were saddened by not being able to take pride in their homes after the stroke. They were now dependent on other family members or hired assistance to complete these activities and tasks.

Participant 6 (rural): "It's bad and I feel like my home is dirty unless I ask somebody to come and smear the wall and floors for me." (6:144)

After the stroke women struggled to participate in these meaningful activities as they struggled with bilateral hand integration and were unable to balance themselves in a kneeling position.

Participant 4 (rural): "It's difficult to use one hand if I have to kneel down, I don't have balance when I do this" [shows how to smear floors].

Interviewer: "What do you use to smear the floors?"

Participant 4: "You use this hand when I am balancing with and you use the other." (4:80)

Participants also had fear of falling when smearing and painting the outside of the hut as they had to balance on an object such as plastic crates or buckets.

Participant 8 (rural): "I cannot stand on my feet, because you have to stand up when you are working. Sometimes you have to climb up on something to reach up there. I don't have a way to do that." (8:221)

4.7.2.2 Acquisition of goods and services

In this section the activities are discussed that relate to the acquisition of products such as food, fuel, water and home utensils

i. Collecting water

Water sustains life and forms an essential part of preparing meals, completing self-care activities such as bathing and household chores such as doing the laundry. The water resources for some of the urban participants all of the rural were outside their dwellings. Women in both settings had to complete additional activities to procure water, which entailed walking to the nearest water source to collect it and carry it back to their dwellings.

Most rural participants had to fetch water from the river, while one participant had a rain-water tank next to her dwelling. Urban participants fetched water from taps in their yard or communal taps. Participants in both settings expressed that they struggled to collect water after the stroke.

Participant 16 (urban): "The only thing I am unable to do is to fetch water. That is the only thing I struggle with. If everything is here, everything is right." (16:99)

Participant 16 (urban): "My main challenge is that I still have to stay here (informal settlement). That is the thing that is making me not right as I have to go and fetch the water. If I can stay in a place that has (running) water my life will be much better." (16:284)

Participant 16 expresses how the environment in which she lives, where she does not have access to running water, is creating a barrier to her participation, not only her current impairments in body function.

Water was often stored in big containers inside the home. Participants in both settings reported that they collected water in smaller bottles compared to before the stroke, as this was more manageable. Urban participants whose water source was closer to home would walk to and from the water source carrying small amounts of water, to fill the bigger storage containers at home. This would take time and increase energy expenditure for women with stroke.

Participant 17 (urban): "I will keep going until the big bucket is full." (17:95)

Rural participants expressed they struggled to collect water as they feared losing their balance and falling over rough terrain and struggled walking such extensive distances.

Participant 6 (rural): "I no longer go to the river as I fall now." (6:63)

Participant 6: "Right now what is happening is that if I have to hold the bucket in one hand, I will lose my balance and I will fall and I will struggle to get up. It is very painful. I fall easily and it's very muddy and there are stones. I will slip and fall." (6:16)

In summary, as all rural participants and some of the urban participants did not have running water inside their homes they had to complete additional tasks in order to provide water for the household. Participants had to collect water from different sources outside their home and carry it back to their dwellings, where it was then stored in larger buckets inside the home.

ii. Sourcing cooking fuel

Participants in both settings reported that they use electricity or paraffin for cooking, but many rural participants still retained traditional methods of cooking on a fire.

Women with stroke in the rural setting expressed that they struggled when collecting firewood from the nearby forest. They would collect pieces of wood and carry it back to their dwellings. The wood would then be stacked next to their dwellings to be used for making fire. Collecting wood was a responsibility expected of Xhosa women.

Participant 5 (rural): "When you are a woman you go fetch the wood..." (5:32)

Many women were unable to collect the wood and would be dependent on family members or had to hire people to do it for them.

Participant 6 (rural): "Even the wood that is outside I paid. I have to hire someone because I cannot go to the forest anymore so I buy it." (6:161)

Women in urban areas had additional financial burdens, such as paying for electricity each month and would at times have to borrow money for this necessary amenity.

Participant 21(urban): "The electricity gets finished quickly and you will not have money as the pay date will still be far. The little electricity in the box is very little and we have to borrow money from people." (21:95)

The women with stroke in both settings reported that they struggled to collect water or wood, because they could no longer place the containers or bundles of wood on their heads.

Participant 17 (urban): "It is difficult for me to put the bucket on my head with only one arm. It becomes difficult to lift the bucket to my head, but if someone is assisting me I can." (17:103)

Participant 2 (rural): "I will not be able to put the wood on my head." (2:70)

iii. Sourcing food

Participants had a major role in providing food for themselves, adult family members and children. Participants in both settings had to procure food by shopping, but rural participants also relied on subsistence farming. Rural women grew their own produce in gardens next to their dwellings or in communal fields within their neighbourhood. Rural women with a stroke reported a strong positive emotional connection and enjoyment associated with gardening.

Participant 9 (rural): "I enjoyed working in the garden" (9:148)

They described how they first ploughed the field and planted the vegetable seeds. Some participants made use of oxen to help with ploughing. While the vegetables grew, they would hoe the ground to remove weeds and maintain the garden. After the vegetables, had grown fully, they would be harvested and carried back to their dwellings.

Participant 12 (rural): "It was to plough the corn and to hoe when the corn grows. When the corn grows old you eat. There comes a time to harvest. Then you harvest your corn and take it back to the house together with the beans. I used to do everything that was done (by women)." (12:28)

The different types of vegetables grown in the rural participants' gardens were corn, pumpkin, cabbage, spinach, potatoes, beans and edible weeds known as *imifino*.

Gardening entailed activities requiring bilateral hand integration. Some rural participants reported not being able to participate in these activities due to limited movement and function in their affected arm after the stroke.

Participant 6 (rural): "To hoe you need both hands to hold the hoe. So I only have one hand. Even if I try to use the other one it can't hold on, that is the reason." (6:19)

Following the stroke, some of the rural women had family members who continued to garden and grow food. However, some participants become more reliant on buying food for themselves and their households. Some expressed that they had inconsistent family support or only younger children to help them. The children often were unable to fulfil the role of providing for the family. This placed a considerable financial burden and subsequent emotional strain on these participants.

Urban participants were solely reliant on buying food for the household. They struggled to buy enough food with their limited funds from the disability grant.

Participant 17 (urban): "The food is not enough. I do buy, but it is still short here in the house." (17:61)

Participants also struggled to go to the shops. Some relied on family members to buy food, usually with their own grant money. Other participants had to rely on people taking them to the shops, and often had to arrange private transportation.

Participant 15 (urban): I don't normally go to the shops; I only go on the 1st when I have to receive my grant there at the mall. I will go there. It's even difficult with the wheelchair as it is always full of the people. It's a bit far so we use to hire car to get there. It will wait for me while I am getting my pay (grant). (15:129)

4.7.2.3 Providing financial support and employment

Most women with stroke in rural and urban settings were previously employed and provided financially for their household. Most of the participants in both settings were previously employed as domestic workers in other households. Only three participants had other means of income generation. Participant 12 in the rural setting reported to be a traditional healer, but could no longer assist in healing people as she was unable to mobilise into the fields and forest to gather medicinal plants. Participant 16 in the urban setting had a small business selling goods in the informal settlement, which she was able to continue but needed to hire assistance to help procure goods. Participant 20 was a registered nurse, but she was unable to fulfil her work responsibilities after the stroke.

The women in the rural and urban settings who worked as domestic workers were responsible for domestic tasks in other people's homes. Activities included looking after children, cooking and cleaning.

Participant 2 (rural): "I looked after the children of that family. I did their laundry and cook and clean the house." (2:17)

None of the women previously employed as domestic workers were able to return to work. They were unable to complete domestic tasks due to poor bilateral hand integration, difficulty with carrying objects, mobility and balance. They questioned who would be willing to hire them and raised concern that employers would not be satisfied with their work if not done properly.

Participant 6 (rural): "I no longer work now, because I cannot. I will just be sitting and it will be more like I am stealing someone's money, because I cannot do anything. If I have to cook she (child) peels for me. If I have to sweep and take a mop it's like I am robbing them, because I can't do things as I use to. I cannot dust high places, because I am scared to fall." (6:37)

Being unemployed was expressed as a huge burden and stressor for these women. Women who were previously employed stated that they struggled to make ends meet with only a government grant. It was difficult for them to buy enough food and clothes for themselves and their children. Women in urban areas described more financial stressors compared to rural participants.

Participant 17 (urban): "It hurts as I have children." (17:15)

Participant 21 (urban): "Yo, it has changed so much Sisi, I do not want to lie. I even lost some weight because I am not used to stay here and look at a small amount of money. It doesn't solve all the problems here; it just covers the food that R1000. I can't afford clothes, I have nothing." (21:57)

Participant 17 (urban): "It is really difficult now that I am unemployed as I can't afford the things that I am supposed to do with just my disability grant." (17:59)

Not only were they unemployed and had to make ends meet with the government grant, but they now had more expenses than compared to before the stroke. They were forced to pay other people to do activities related to their domestic roles, which they found frustrating.

Participant 6 (rural): "Sometimes if you need to smear the lime you will need to hire somebody and pay more money. Now it has changed as it is me who has to pay for everything. Even the wood that is outside I paid. I have to hire someone because I cannot go to the forest anymore so I buy it." (6:159)

Participant 16 (urban): "I ask people to go and fetch water for me." Interviewer: "Do you pay these people who fetch water for you?" Participant 16: "Yes, always. You pay for the people here." (16:21)

Participant 8 (rural): "Nothing that people do, unless you are going to pay someone then they will do what you want." (8:232)

Participant 21 expressed that she would prefer living in a rural area as it was perceived to have more support and quality of life for those who are unemployed.

Participant 21 (urban): "We are really planning to be permanently on that side (Eastern Cape), because staying in town is not for people who are doing nothing (unemployed). It's worse for people who used to do everything by yourself. That is something that is hurting me badly." (21:193)

Despite this woman's perception, study participants in both settings reported financial burdens, especially if they received inconsistent family and social support.

Government grants were said to be less than what participants had previously earned, but were still seen as facilitators to sourcing products and services, and caring for family members. The government grants allowed participants to continue providing for their households.

Participant 8 (rural): I do look after them (children) because I feed them. I buy food for them so they can cook it and feed me." (8:58)

Participant 5 in the rural setting was particularly satisfied with receiving a grant as she did not work before the stroke and had comprehensive support from other family members which could assist with tasks around the home and not have to pay other people to do it.

Participant 5 (rural): "I am not struggling because I get the money (receive the grant). I got the money from the hospital from the doctors, so now I don't see anything that is troubling me." (5:5)

4.7.2.4 Environmental factors influencing the role of provider

Women in rural areas had far more activities outside their homes that related to providing for their households. The rural environment was rich in natural resources which they used to build structures, maintain their homes, source food through gardening and collect firewood for cooking fuel. In the urban areas participants had fewer natural resources and were reliant on buying goods and hiring services to build or repair their homes.

Due to lack of basic amenities such as running water inside both the rural and urban homes, the women had to complete additional tasks to procure water for their households.

Participants in the urban environment experienced financial strain in procuring cooking fuel and food. Participants in both settings incurred additional expenses in hiring assistance with manual tasks.

Although the natural resources in the rural setting were freely available, the tasks associated with extracting these resources were labour intensive. Such activities required them to use both upper limbs and mobilise long distances over rough terrain while often balancing something on their heads, which participants struggled with after the stroke. The lack of basic amenities, such as toilets, also resulted in additional tasks that had to be completed to fulfil basic needs.

Government grants are facilitators that help participants who are unable to work to afford food or services. However, many participants struggled to make ends meet as the grant amount was less than what they earned while employed.

4.7.2.5 Personal experiences of fulfilling the role of provider after a stroke

In the rural setting the activities associated with home maintenance were viewed as meaningful and provided enjoyment. These were activities they had been taught from a young age, and it gave them pride to make their homes look beautiful.

Due to the intensive manual labour required in completing these tasks, none of the women were able to do them anymore. If family members in the rural setting were not able to fulfil these responsibilities, the women with stroke experienced a loss of role, which influenced their self-worth. They could no longer participate in meaningful activities and could not take pride in their homes. For the younger women, it also meant that they were unable to fulfil the role of the newlywed wife, and if they were single it would make them unsuited for marriage.

Participants in both settings expressed financial strain from no longer being employed. Despite the assistance of government grants for acquiring necessities, this was often viewed as not enough. There was also a sense of role reversal as the participants used to be employees themselves, working to generate an income to support their families, but now they had to employ other people to fulfil their responsibilities.

4.7.2.6 Summary

In this role of provider, rural participants reported that activities extended outside of their homes. The activities that were performed outside included sourcing food from the garden, cooking on the fire and the activities involved in building and maintaining traditional dwellings.

Women with stroke who had migrated to the urban setting also referred to many activities and responsibilities that they retained when returning to their family home in the Eastern Cape. They would work in the garden, assisting with ploughing and hoeing, and would also smear the walls and floors of their homes.

Although urban participants expressed a bigger financial strain providing for the household as they were reliant on buying food and paying rent, participants in both settings had additional expenses, particularly if comprehensive family support was not present. The government grants assisted in providing basic necessities, but were not seen as enough to provide and care for their family members and households.

4.7.3 Caregiver

The study participants in both settings not only had to care for themselves, but also for others. All participants reported responsibilities of caring for children and a few had to take care of adult family members too. The most common activities relating to these roles were preparing food, cooking and doing laundry. Participants who looked after children struggled to change nappies, bath and dress the children including taking them to school or crèche. In the hierarchy graph in figure 4-22 the caregiver role responsibilities and activity requirements are summarised. The activity and task requirements, including the influence of environmental factors, are reported further in this section.

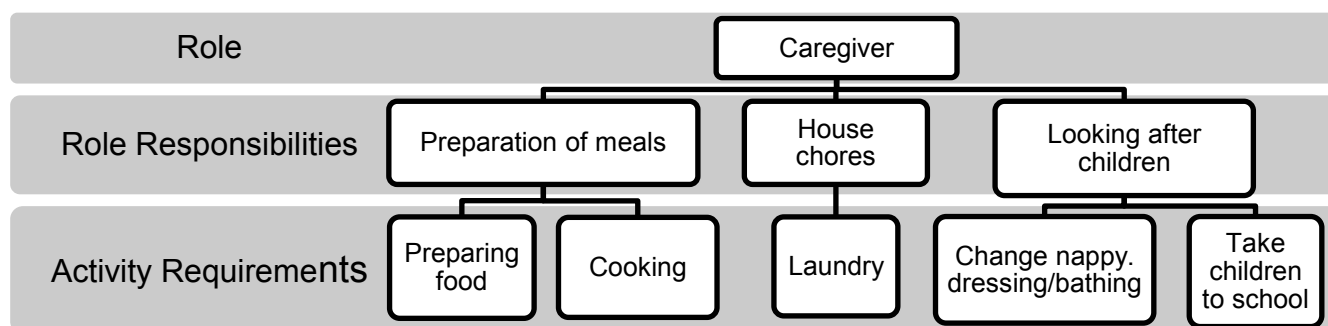


Figure 4-22 Caregiver role, responsibilities and activity requirements

4.7.3.1 Preparation of meals

Women in both settings had the responsibility of preparing meals for their households. Women with stroke in both settings expressed difficulties with similar activities, such as cutting and peeling vegetables.

Participant 20 (urban): "Like I can't peel butternut, cabbage, everything I want to do. And that I am struggling to do is... aai man there are many things." (20:9)

Participant 21: "I can't peel potatoes. I can't cut cabbage." (21:83)

Before the stroke participants would often sit on the floor with their legs straight in a long sitting position while cutting vegetables. Participants in both settings expressed that they enjoyed sitting in this position even outside the homes and at work. They enjoyed being able to stretch their legs.

Participant 16 (urban): "I will also sit and really enjoy sitting on the floor. Even here I do sit on the floor." (16:217)

Participant 21 (urban): "Yes I will stretch. I use(d) to enjoy stretching like that. Even at my work my employer will come and I will be stretching on the floor." (21:135)

Transfers to the floor after the stroke were however problematic and participants required assistance to sit on the floor and to get up again. Family members had to assist with transfers to and from the floor.

Participant 4 (rural): "I cannot sit on the floor, because I cannot balance. The problem is this side." (4:169)

Participant 5 (rural): "She (family member) will hold me and I will assist until I sit down on the floor and stretch." (5:162)

Rural participants however had additional tasks relating to food preparation. Rural households were dependent on growing and harvesting their own vegetables rather than buying processed food. This meant additional activities to prepare vegetables and other produce such as maize for cooking. Food often prepared by rural participants included samp and beans (*umngqusho nenooyi*), maize and edible weeds grown in the fields (*imifino*).

Participant 5 (rural): "I use to cook Xhosa food. You know the plants (imifino), I would cook it and grind (corn for maize)." (5:14)

To prepare these meals participants first had to take dried out corn and remove the kernels from the cob. For samp and beans, the corn kernels would be mixed with the beans and then cooked together. These activities are traditionally also done while sitting on the ground.

“Participant 10 (rural): I will remove the pit from the corn until that small basin is full. And then I will prepare the beans.” (10:174)

Grinding corn to produce maize entails using a level slate and a round stone. Participants perform the activity on their knees. The rural participants were unable to grind the corn as it required bilateral hand integration and their affected upper limb could not assist with the task.

Interviewer: “why do you not grind the corn anymore?” Participant 10 (rural): “I don’t have a hand.” (10:43)

Grinding corn is also an activity involved in preparing traditional beer, which was always the women’s role. The preparation and drinking of traditional beer is a central feature in Xhosa culture, and signifies giving praise and receiving blessing from the ancestors, especially at ceremonial events such as the return of young men from initiation school and traditional weddings.

Participant 10 (rural): “I use to grind myself and I use to brew traditional beer (ukusila umqomboti). After I was attacked by the stroke there is no one to brew.” (10:271)

If the household did not have anyone to brew traditional beer, they could not offer any praises to the ancestors and received no blessings.

Cooking food was expressed by many participants as difficult after the stroke. It was also seen as an essential role in caring for their children and households. It was also considered a meaningful and valued activity allowing them to choose what they wanted to eat.

Participant 5 (rural): I would like to be able to cook so I can eat the things I like. (5:12)

Both rural and urban participants made use of electricity, if available, as cooking fuel, with electrical appliances such as stoves or stove tops. Urban participants mentioned often running out of money to buy electricity and which then necessitated the use of paraffin stoves.

Participant 21 (urban): “The electricity gets finished quickly and you will not have money as the pay date will still be far. The little electricity in the box is very little and we have to borrow money from people... I have to make means to get money to buy a litre of paraffin so we can use the heater to cook.” (21:95)

Urban participants preferred paraffin stoves over gas due to the cost, availability and fear of gas explosions in informal settlements.

Participant 19 (urban): "The problem is the gas is scarce and there are children who will open it." (19:165)

Participant 19 (urban): "Its danger is that if you turn it on its will smell in the house. Then when you arrive and light with the matches it will explode." (19:171)

Not all the participants in the rural setting had access to electricity or electrical appliances for cooking. Instead, they would make use of paraffin stoves for cooking inside the home. If electricity or paraffin were available for cooking, rural participants did not experience major restrictions in preparing a meal. Despite rural participants having access to electricity many rural households still made use of outdoor cooking fires, either in the open or in a protected structure. Women with stroke found this difficult to manage.

Participant 5: "I will make a fire at the fireplace and cook there. I would go fetch some wood..." (5:21)

The participants used big black cast iron pots to cook in on the fire. Traditional beer was also cooked in these pots on the fire. Most participants reported that they struggled to carry these pots and would have to ask for help from family members or neighbours.

Participant 3 (rural): "It is also very difficult to make fire outside as a traditional woman." (3:5)

Making a fire and cooking on the fire was also seen by the women as a traditional task. After the stroke, most of the participants were unable to participate in this meaningful activity. Preparing a meal on the fire was also a prominent aspect of traditional events and rituals, in which many participants were unable to participate after the stroke

Independence in preparing and cooking food were limited by mobility and bilateral hand integration, due to limited movement in the affected upper limb. Participants described difficulty in holding and carrying pots while cooking. They also expressed a fear of burning themselves.

Participant 2 (rural): "I cannot cook now. I feel like I will burn." (2:60)

Participants also expressed a role reversal in the households where they used to feed family members and children, but now they were being fed.

Participant 8 (rural): "I will also dish for them and they will eat it. Now it has changes. They cook and dish out for me. I feel like a baby now and they must look after me." (8:68)

4.7.3.2 House chores

Both participants in rural and urban settings were responsible for doing the laundry. However due to environmental factors the requirements of doing the activity were different in each setting. The urban participants did their laundry inside their home, but said they struggle with it.

Participant 16 (urban): "The only thing I struggle with is the laundry." (6:3)

The participants mainly washed their clothes by hand using a washing basin. They struggled to do this as their affected upper limb was unable to move and grip as needed.

Participant 14 (urban): "I use to wash it with my hands. Now they don't work." (14:17)

When doing laundry by hand many urban participants reported sitting on the floor. Some urban women with stroke had access to an electric washing machine and did not report any difficulties in washing the clothes and could hang the washing up themselves.

The rural women with stroke expressed that they would usually do their laundry at the river before the stroke. Women in rural areas did not have running water inside or next to their homes. For laundry, a large amount of water is needed to wash and rinse the clothes and especially traditional blankets. The participants would have to take the clothes and blankets in a washing basin to the river. There they would wash it and either leave it there to dry or carry it back home to dry closer to home.

Participant 5 (rural): "You do the washing you go to the river and wash your clothes." (5:36)

Participant 6 (rural): "I use to go to the forest to the river. I used to put the big washing basin (ibath) on my head and carry it to the river and wash it and bring it back and hang it here at home on the fence." (6:59)

Participants expressed that they struggled to do the laundry as they were unable to put the basin on their head and some struggled with balance whilst walking to the river.

Some of the rural participants showed resilience in finding ways to overcome their restrictions by adapting tasks such as placing the basin on their heads. Children were also often involved in helping with the tasks that the women with stroke could not complete.

Participant 3 (rural): "I will put the clothes in the washing basin (ibath /bucket) and then place it on top the chicken coop. I will swing it up on top of my head. Then I will walk to the river with washing basin (ibath) and wash the clothes there. I will leave them there for the children to fetch it." (3:11)

Doing the laundry at the river was often also a social event for women where two or more would go together. On hot days, they would even have a proper bath in the river.

Participant 8 (rural): Sometimes we will also wash our blankets (iimbayi) at the river then we will also wash our bodies. (8:191)

4.7.3.3 Looking after the children

Most of the rural and urban participants reported that they had to look after younger children who were still dependent on them. In both settings, the women were not only required to look after their own children, but also other family members' children.

This was especially true in rural settings, where the children's own parents were deceased or had migrated to urban areas to find work.

Participant 6 (rural): "Those who are here are my sisters. They are the ones that are supposed to look after me if we are all staying together, but they are not here... They went to find employment as domestic workers." (6:92)

As discussed, before the stroke the participants were responsible for preparation of the meals for the children and doing laundry. They also had additional responsibilities in looking after younger children who were more dependant. The activities and tasks that the women with stroke were expected to do but struggled with were washing the children and helping to dress them. If the child was still a baby, they would struggle to hold them and change their nappies.

Participant 4 (rural): "When the baby is crying I cannot look after her as I can only use my one hand. When I hold her with one hand she cries." (4:33)

Participant 6 (rural): "To change no I can't my dear. I don't even want to lie. I will be lying. I use to change her before when I was still alright. I knew that when the child is wet I have to change the nappy, I had to wash her, but now she waits for her mother." (6:122)

The women struggled to look after the children themselves, because their affected upper limb could not assist in activities. Women with stroke were dependant on family members and older children to assist. Some women often had to give instructions to the other children.

Participant 6 (rural): "Now I just give them orders like: get the washing basin, take the kettle and plug water like this and pour the water and then wash yourself. And take something to smear yourself..." (6:85)

Participants in rural and urban settings reported that they had a loss of authority when giving instructions or orders. The children did not respect them, because due to their impairments they would be unable to discipline their children.

Participant 15 (urban): "Here at home I have to make sure that the children go to school and clean and also teach them their own chores here at house... (after the stroke) Not really do them now. I just tell them and sometimes they just ignore me, because they don't see me standing up. I just talk to the word of mouth and sometimes I get tired." (15:65)

Rural and urban participants reported that they would have to make sure the children went to school, and some would accompany their children to school. Most urban participants reported that the children were old enough to walk independently to school. Participants in urban areas were unable to take children to school due to struggling to walk so far.

Interviewer: "Why do you no longer take them (children to school)?"

Participant 19 (urban): "No... The problem is I am unable to walk long distance." (19:66)

Participants were dependant on other family member to take children to school. None of the rural participants reported any restrictions in taking children to school, which is more an indication of the children walking together than the impairments faced by women with stroke.

4.7.3.4 Environmental factors influencing the caregiver role

Participants in both settings reported that if they had electricity or a paraffin stove, they would prefer cooking inside their homes. However rural participants at times continued using a fire to cook on despite the availability of electricity. Not only did this involve the additional task of procuring firewood, but it was also much more labour intensive to make the fire and cook on it.

Participants in both settings struggled with food preparation. However, as the rural participants grew and harvested most of their food they had additional tasks relating to food preparation that were often executed while sitting or kneeling on the floor.

Access to running water also influenced the task requirements of the laundry in a household. Urban participants who had access to running water inside the home or in their yard would do the washing inside the home. Some participants even had access to electric washing machines. In the rural setting participants had to carry their laundry to the river as running water inside or close to the house was not available.

The activities and tasks associated with looking after children were similar in the rural and urban environments.

4.7.3.5 Personal experiences of fulfilling the role of caregiver after a stroke

Participants expressed that preparing meals for themselves and their households was a meaningful activity. They took pride in making food that they and the family enjoyed.

Participant 15 (urban): "I must say I used to cook the food that my children would love." (15:77)

After the stroke, women struggled to prepare meals and were more dependent on other family members to do this. Despite assistance from family members, participants felt that they lost the autonomy to choose what they wanted to eat.

Participant 5 (rural): "The only thing that is challenging is when you are struggling while you are like this, unable to cook...I would like to be able to cook so I can eat the things I like." (5:6)

Some rural participants expressed that they no longer could make traditional beer, which had cultural significance in their role as women which would be lost if there was no one else in the home to continue the activity.

4.7.3.6 Summary

Within the role of caregiver, participants from both settings had similar activity requirements for the preparation of food, such as cutting and peeling vegetables. The rural participants however had some additional tasks, including grinding corn in traditional apparatus. The urban participants had other domestic tasks such as laundry that was completed inside the home, but rural participants did their laundry outside their home.

4.7.4 Community member

In this section, the most common community and social activities which rural and urban women with stroke used to participate in, are discussed. Religion and going to church were an integral part of community life for women with stroke in both settings. Women with stroke in rural and urban areas expressed that they previously attended community meetings. Rural participants additionally participated in traditional and cultural events. In the hierarchy graph of figure 4-23 the community member role responsibilities are summarised.

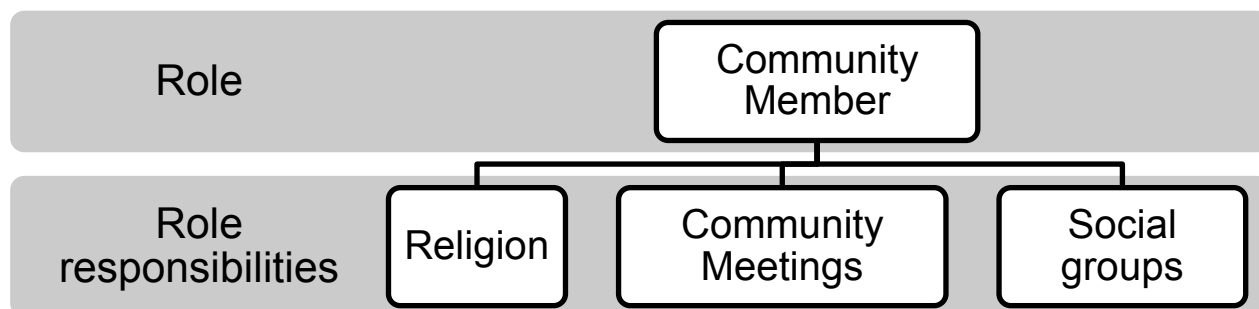


Figure 4-23 Community member responsibilities.

4.7.4.1 Religious activities

Transportation to religious events was problematic for most rural and urban women with stroke. In the rural setting women with stroke used to walk to church and were unable to do so now. In the urban setting, they used taxis or public transport to travel to church. Some participants in both settings however were unable to return to church gatherings as they were unable to mobilise in their community and access transportation.

Participant 4 (rural): "I used to go to church, but I can't anymore... I used to like it. It is too far and I get tired while I am still walking." (4:100)

Participant 21 (urban): "Like now there is even a church in faraway places like in Nyanga. I can't get to Nyanga as I take a bus and it is a distance between the house and the bus stop. Those are the things I am unable to do now." (21:169)

Rural participants who were unable to go to church often found that church members came to visit them at home. They also received emotional and at times financial support from the church.

Participant 11 (rural): "I no longer go (to church). They come here now... They will come and praise." (11:186)

Participant 21 (urban): "It's mostly church people who assist me... When there is no electricity they will be able to give us a R50 so we can buy electricity." (21:166)

4.7.4.2 Community meetings

In rural areas, the community meetings are held at the local chief's home, where all community members come together to discuss important matters.

In the urban setting community meetings are also referred to as street meetings, and are where sections of the community come together in a town hall or communal place to discuss important matters with ward councillors.

Attending community meetings in the rural setting was a requirement for family elders or the heads of households. Younger participants reported that it was not their responsibility, but rather their parents who had to attend the meetings. However, some younger participants who were the head of their household had to fulfil the responsible of attending community meetings.

Participant 6 (rural): "...now that my father passed on I am the eldest now and I am forced to act like a mother and go... It's a must that I must go. If I don't go I need to report that explains why I didn't go. Sometimes I will not feel alright or sometimes the weather is bad then I get scared." (6:173)

Rural participants reported that before the stroke they used to walk to events in their communities.

Participant 5 (rural): "I would walk with my feet to there (community events). I was still able to walk back then." (5:46)

Women with stroke in rural and urban settings used to participate in community meetings, but struggled to continue their involvement due to mobility problems and inability to participate in preparation activities. Other community members or elders would therefore come and relay information to them at home.

After the stroke, participants in both settings were dependant on transportation to reintegrate into their communities. Accessing transportation with limited mobility was often problematic and participants would either be dependent on family members to escort them to transport; or in many cases the women stopped attending community events all together.

4.7.4.3 Social Group Member

Women in the rural setting were an integral part of cultural events such as weddings or funerals where they would prepare the meals and traditional drinks. Some participants also recalled enjoying singing and dancing during these celebrations.

Participant 12 (rural): "It would be anything even if it was a wedding or if the woman is sent to her in laws even if it's a traditional event whereby there would be a slaughtering. They will fetch the wood and we will prepare and cooking including traditional drinks (amarewu). We will drink and then slaughter." (12:145)

In urban areas, women with stroke reported being part of funeral or social clubs where they would contribute financially each month to the group. When there was a death in one of the members' families, the group would go to their home to assist with funeral preparations and give financial support. The participants struggled to participate in these events as they struggled to mobilise to other people's homes and struggled to assist with preparation.

Participant 21 (urban): "For example we were doing the things we were doing like if there is death in the household, we will go and assist there. I can't do as I used to do anymore... I can't assist in anything even if there is death in a particular household; I cannot go and assist. I just stay here in the house as I couldn't assist even if I go. What if I drop people's stuff and it breaks." (21:65)

4.7.4.4 Environmental factors influencing the role of community member

Community re-integration was restricted in rural and urban settings due to problems with community mobility and access to transport. Transportation in rural areas was often inconsistent especially when it was raining.

4.7.4.5 Personal experiences in fulfilling the role of community member

Women in the rural setting reported more often than urban participants that they received support and felt part of their communities. Community support in the rural setting was illustrated by people allowing women with stroke to sit in the front of the taxi so that it was easier to transfer in and out of the vehicle.

Participant 6 (rural): "that time they will ask someone who sat in front to change seats with me as I was unable to get to the back... For example if it is you who is sitting in front they will ask you to go and sit in the back and I will sit in the front. They will assist me to sit..." (6:281)

Community members in rural setting also understood the women's limitations and would assist them in church and social events and share food if they ran out.

Participant 10 (rural): "Sometimes I run out of food so they will give me money." (10:327)

Participant 8 (rural): "Sometimes I will run out of food and they will then come and offer me food so that I can eat. The food we buy with this grant pay gets finished. Then they will bring food so that I can eat." (8:229)

Even within their families they still played a part in their family structures.

Participant 5 (rural): “Sometimes the problem is there by them (family). As you know, I am a daughter at my father’s family and they have to include me, even if I am like this now. Even if I am this scrap I am still a daughter and they must come and fetch me.” (5:141)

Despite support offered by community members, both rural and urban participants, especially younger women, expressed that their social interaction with friends diminished after the stroke. Participants used to go out with friends, but as the time continued after the stroke, support from friends dwindled.

Participant 20 (urban): “Oh before the stroke, I use to go (out) a lot; I had a lot of friends. I use to go to my friends and go to the movies and everything we do.. aah you see now. When days are dark, no friends.” (20:79)

4.7.4.6 Summary

Participants in both settings reported that they were less involved in community activities since the stroke. Community mobility and access to transportation were often expressed as restricting factors.

Rural women with stroke expressed that they received support from community members to use transportation more often than urban participants did. However, some participants in rural and urban settings expressed that religious groups and community members would visit them at home to give support and relay information.

Social isolation was a general trend in both settings. Younger women with stroke in particular reported less social interaction with friends and participation in age appropriate activities.

4.8 Activity and participation experiences in relation to the life roles of Xhosa women with stroke in rural and urban settings.

In this section, three major themes are discussed in relation to the participants’ personal experiences of living with a stroke in their context.

4.8.1 Theme 1 – “I struggle with nothing, they do so much for me”

Within this theme, participants expressed doing very little around the house compared to before the stroke. Ironically, some participants even reported not struggling with anything, because they were not doing anything.

Participant 14 (urban): "I can't say anything now (I struggle with), because I am just sitting here doing nothing. There is nothing that I do." (14:9)

Participant 5 (rural): "There is nothing (I struggle with), because I am not doing anything now." (5:9)

At first glance the participants seemed to express almost a loss of hope, as they could not fulfil their responsibilities or participate in previously meaningful activities. However, they had comprehensive social support from family, who assisted them as needed and took on the responsibilities that were previously placed on the participant. It was for this reason that they did very little as compared to before the stroke.

Participant 11 (rural): "They look after me. If I need something I will just say: children I need something and they will bring it. Children I need to drink and the child will bring the water. If I need something and they will give me whatever I need." (11:451)

Participant 5 (rural): "There is nothing more than she (sister) already does. She does so much for me. She cooks for me and she washes my clothes." (5:206)

Despite some of these participants' low functional level, they were re-integrated into their homes, assisted, cared for and provided for. Family members took up the responsibilities of assisting them with selfcare, providing subsistence and home maintenance. These women also still felt part of the community, as people would come and discuss what was said at community meetings. Religious groups would also come to their homes to give praise.

Participant 11 (rural): "I no longer go (to church). They come here now." (11:186)

Family fulfilled the responsibilities the women previous held within their life roles, but participants felt that despite their impairments, they still maintained their ascribed status. This helped maintain their identity within their families and gave them a sense of self-worth despite the loss of other roles and abilities.

Participant 5 (rural): "As you know, I am a daughter at my father's family and they have to include me, even if I am like this now. Even if I am this scrap I am still a daughter and they must come and fetch me." (5:142)

In this theme, participants had relinquished some of their roles to family members. They had accepted their impaired abilities and dependence on others, but still maintained the roles that were most important to them. The only loss they then experienced was their autonomy. They were reliant on others for where they wanted to go, whom they wanted to interact with or even what they wanted to eat.

*Participant 5: "I would like to be able to cook so I can eat the things I like."
(5:12)*

4.8.2 Theme 2 – "I still like looking smart"

Within this theme, participants expressed a sense of self-worth in wanting to participate in life roles and valued activities. Participants refused to give up their freedom of choice and their independence associated with their roles.

Participant 16: "I try by all means to do things by myself." (16:59)

The participants required assistance to fulfil their roles and activity requirements due to their physical limitations. They needed to ask for help from family members and neighbours or hire assistance. Their lack of independence frustrated participants, and also placed an added emotional and financial burden.

Participant 17 (urban): I don't feel good. I have to ask other people to do things for me." (17:45)

Participant 16 (urban): "I ask people to go and fetch water for me. Interviewer: "Do you pay these people who fetch water for you?" Participant 16: "Yes always. You pay for the people here." (16:21)

Despite limitations in their independence, participants expressed a sense of pride and self-worth in who they were, the status they occupied and the roles they played. Participants were determined to have meaningful experiences, be more independent and strategise on how to fulfil their roles.

Participant 6 (rural): "I still have to go to the hairdresser and pay so they can do my hair and I look smart... I haven't given up on my life." (6:43)

4.8.3 Theme 3 – "Dead, but alive"

In this theme, there is a general reference to loss after the stroke. Participants could not fulfil their roles associated with being a Xhosa woman. They were now no longer the caregivers, but needed care. But due to poor social support and isolation the roles and responsibilities could not be transferred to other members of their family. Participants only received assistance with basic needs. This led to a subsequent loss of identity.

Participant 12 (rural): Now I am dead, but alive. (12:130)

Within this theme, participants felt that after the stroke, everything in their lives came to a standstill, and the responsibilities of being a Xhosa woman were no longer fulfilled.

Participant 15 (urban): "There were a lot of things I was looking forward to do, but I have been attacked by the stroke and that has caused everything to stand still." (15:161)

The participants expressed their own loss of role in their household and community, but also a strong loss of hope in their own abilities to participate in all previous life roles.

Participant 18 (urban): "I do everything here on in bed. I am more like a baby, even younger than this one right here (pointing at the small child)." (18:37)

Participant 12 (rural): "No one is assisting me with anything. I am just sitting here miserable every day with this thing I got that is only mine. I cannot blame people; I just stay as I am." (12:338)

Participants only received the basic assistance from family members, who were often younger children. However, not all of the responsibilities held by these participants before the stroke could be passed on to other family members, and many relating to providing and caring for the wellbeing of the household were lost. Participant 10 expressed that after the stroke there was no one available to brew traditional beer, which was a significant responsibility for Xhosa women.

Participant 10 (rural): "I use to grind myself and I use to brew traditional beer (ukusila umqomboti)... After I was attacked by the stroke there is no one to brew." (10:271)

Participants felt that other family members and children were not fulfilling their roles of caring physically and financially for the household, and thus these roles were lost.

Participant 10 (rural): "My challenge is my son who cannot get employment. That really hurts me badly." (10:33)

Participants also expressed a loss of authority in the household after the stroke.

Participant 15 (urban): "Here at home I have to make sure that the children go to school and clean and also teach them their own chores here at house... (now after the stroke) Not really do them now. I just tell them and sometimes they just ignore me, because they don't see me standing up. I just talk to the word of mouth and sometimes I get tired." (15:65)

Participants also expressed a loss of authority within their community.

Participant 10: When someone is shouting at them I get so hurt I respond. Someone will say what I will do while I have the stroke. That hurts me badly. (10:76)

4.8.4 Triangulation of complementary data sources

The various data sources used in this study had some overlap, and were not always consistent with one another. The reasons for this will be discussed further in Chapter 5. In this section, some of the complementary data from the D&E questionnaire, BI, EQ-5D and SSI will be compared side-by-side.

4.8.4.1 Mobility

The BI showed 72.7% of the rural participants and 77.7% of urban participants reporting that they were either independent or needed minimal assistance with mobility over an even terrain. This contradicts the findings of the EQ-5D, which showed that over fifty percent of both rural (54.6%) and urban (55.5%) participants reported moderate to severe problems with mobility.

In the D&E questionnaire most rural (81.8%) and urban (88.9%) participants reported that they could mobilise around their homes, while 72.8% rural participants and 44.4% of urban participants felt they could mobilise in their community.

The possible reasons for the disparities between the findings related to mobility is the different mobility requirements assessed in each data source. The BI measures the ability to mobilise over even terrain, which within the context of the participants was usually only applicable within their own homes. However, the EQ-5D adopts a more general and functional interpretation of mobility, which could include mobilising indoors or outdoors to perform task or activities such as carrying water or going to the toilets. These findings will be further discussed in chapter 5.

4.8.4.2 Self-care

The EQ-5D assesses self-care as the participants' ability to wash and dress themselves. The median score for ordinal data of the EQ-5D in the self-care dimension highlighted that rural participants experience less problems with these activities compared to urban participants who experienced moderate problems.

The BI assesses self-care activities such as bathing and dressing separately. The Barthel Index's median score for dressing in both settings were 5 out of a possible 10 which indicates most of the participants needed assistance to complete the task. However, the Barthel index also reports that over half of the urban participants (55.5%) were dependant on others in

bathing, compared to only 18.2% in the rural setting. The median score for bathing in the rural participants was 5 (0-5) which indicated that a majority were independent compared to 0 (0-5) for urban participants which indicated that the majority were dependant.

In the qualitative SSI, all participants were asked about their experiences with bathing. In both settings, participants reported that they struggled with bathing, however six (66.6%) urban participants expressed struggling with bathing compared to only three (27.3%) in the rural setting.

Using the BI, EQ-5D and qualitative information, it can be deduced that, despite participants in both settings experiencing problems with self-care activities such as dressing, the urban participants reported more problems associated with bathing compared to the rural.

4.8.4.3 Triangulation of qualitative enquiry themes with quantitative and demographic data sources

The study participants were grouped according to their association with the emerging themes. The EQ-5D VAS score for participants perceived HRQoL and total Barthel Index were compared between the different groups.

Table 4-2 summarises the rural and urban study participants associated with each emerging theme including their median EQ-5D HRQoL VAS and total Barthel Index scores

Table 4-2 Ages and functional outcome measures for participants categorised under the three themes

Theme	Setting	Participants	EQ-5D HRQoL VAS (out of a 100)	Barthel Score (out of a 100)	Ages (years)
Theme 1:	Rural	P2	80	85	31
		P5	60	60	42
		P11	80	40	66
	Urban	P13	90	90	59
		P14	65	70	65
	Median (range)	n=5	80 (60-90)	70 (40-90)	59 (31-66)
Theme 2	Rural	P3	50	80	57
		P4	40	85	24
		P6	60	95	32
		P9	50	90	26
	Urban	P16	60	100	36
		P17	60	100	42
		P19	55	80	31
		P20	50	65	52
	Median (range)	n=8	52.5 (40-60)	87.5 (65-100)	34 (24-52)
Theme 3	Rural	P8	35	55	72
		P10	30	50	56
		P12	35	80	62
	Urban	P15	35	65	57
		P18	20	10	56
		P21	20	85	56
	Median (range)	n=6	32.5 (20-35)	60 (10-85)	56.5 (56-72)

As seen in table 4-2 there is a marked difference between the EQ-5D scores in the three different themes. Participants associated with the theme1: “I am doing nothing” have the highest EQ-5D VAS score followed by theme 2, and participants in theme 3 had the lowest EQ-5D VAS score.

4.9 Conclusion

In this chapter, results from both the quantitative and qualitative data have been presented. The quantitative data was collected through the demographic and environmental (D&E) questionnaire, Barthel Index and EQ-5D.

The D&E questionnaire results highlighted that the rural participants were slightly younger than the urban counterparts and rural participants had higher self-reported HIV prevalence compared to urban. The natural and human made environmental characteristics were vastly different in rural and urban areas. The majority of rural participants had no access to running water, but rather had to collect water from rivers. Rural participants also had to mobilise further to access toilet facilities and a third of rural participants preferred the natural environment for toileting purposes. Despite the majority of rural participants having access to electricity they still used traditional outdoor wood-fire cooking methods. Children also played a larger supportive and caregiver role in the rural setting.

Participants in both settings accessed primary healthcare services such as clinics, where they would predominantly see a nurse and at times a doctor. Half of the rural participants however accessed physiotherapy services at primary healthcare facilities compared to none of their urban counterparts.

The level of function as determined by the total Barthel score was similar for the rural participants and urban participants. Rural participants scored higher with independence in bathing and mobility. Urban participants scored higher in independence in feeding and transfer abilities. Rural and urban participants had similar scores for activities such as grooming, dressing and toilet use, including bladder and bowel function.

HRQoL VAS scores on the EQ-5D for rural and urban participants were very similar. The rural and urban participants had similar experiences in the health status dimensions of mobility, usual activities and pain. Rural participants had better experiences in the health status dimensions of self-care and depression and anxiety compared to urban counterparts.

The qualitative data was obtained through SSI's. The life roles expressed by participants that related to their status of being a Xhosa woman were: self-care, provider, caregiver and community member. The themes emerging from the personal experiences of participants living with stroke and trying to fulfil their roles were:

Theme 1: "I struggle with nothing, they do so much for me" In this theme the participants expressed that they do not participate or fulfil their roles, but have comprehensive support from their families, who assist in caring and providing for them. These participants presented with high HRQoL VAS scores.

Theme 2: “I still like looking smart” – In this theme the participants expressed a drive to be more independent and continue to fulfil their life roles. However due to their impairments after the stroke, participants needed to ask for assistance from family members or hire assistance. Participants continue to strategise to be more independent. These participants presented with medium/moderate HRQoL VAS scores.

Theme 3: “Dead, but alive” – In this theme participants expressed a loss of hope as they could not fulfil their roles and perceived to have very little social support. Participant feels that family members were not fulfilling their new roles in caring and providing for the participants and thus roles were lost. These participants presented with low HRQoL VAS scores.

The qualitative and quantitative data provides a better understanding of the participants’ ability to participate in activities to fulfil their life roles. The data also gives insight into how environmental factors shape these activities, and personal factors influence their re-integration into their homes and communities. The following chapter will discuss these findings along with other literature.

5 Chapter 5 Discussion

5.1 Introduction

In this chapter, the qualitative themes and descriptive categories described in chapter 4 are compared and contrasted with the quantitative findings, and with the literature, in order to describe and compare the activity requirements and experiences of Xhosa women with stroke in relation to their life roles in rural and urban setting. The first section compares the demographic characteristics of the participants with current literature on stroke epidemiology, and reviews the implications for the life roles and responsibilities of these women. In the second section, the influence of environmental factors on the activity requirements to fulfil life roles are discussed and compared between both study settings. In the third section the personal experiences of women with stroke and their perception of their social support are discussed.

5.2 Participant demographics and their implications for life roles

The median age of participants in the rural setting classified them as young people with strokes (Griffiths & Sturm, 2011; Marini, Russo & Felzani, 2010), while the median age for urban participants sat on the upper limit of this classification (Smajlović, 2015). The advances made in the medical management of strokes have increased the life expectancy of people with stroke (De Wit, Theuns, Dejaeger, De Vos et al., 2016). In a young person with stroke this results in an increased lifetime burden of disability.

The urban participants had a higher prevalence of hypertension (55,6%) as a self-reported co-morbidity. This is in line with recent literature highlighting increased prevalence of non-communicable diseases such as hypertension in LMIC's. Most urban participants reported to be migrant workers coming from the Eastern Cape. This explains why the mean years lived in one's current setting was lower for urban participants than for rural.

HIV was the highest self-reported co-morbidity in the rural group. This correlates with current epidemiological literature that highlights the association between HIV and incidence of stroke in a younger population (Dobbs & Berger, 2009; Karbasi-Afshar & Izadi, 2014; Sen, Rabinstein, Elkind & Powers, 2012).

It must be highlighted that participants were not asked directly whether they were HIV positive, but simply whether they had any illnesses. The high number of rural participants

willing to disclose their HIV status is possibly a reflection of the standard of services and support structures available in this area. Zithulele district hospital, which serves the Mqanduli subdistrict where participants were recruited, is known to provide high quality HIV care and high-standard ARV programmes (Young & Gaunt, 2014). Patients at the hospital who test HIV positive receive appropriate medical care and are initiated on HAART treatment, in addition to receiving ongoing support from lay counsellors and peer educators (Young & Gaunt, 2014).

This study reflects current literature describing South Africa's health transition, characterised by the increased prevalence of cardiovascular risk factors, including NCD's such as hypertension, in parallel to communicable diseases such as HIV, especially in rural areas (Kahn, 2011).

The young median age of participants in this study raised important considerations about the roles they had to fulfil, which included not only having to care for themselves, but also providing and caring for their families, and being an active member of their communities. The activities required to fulfil these role responsibilities were influenced and shaped by the participants' environments. A person's identity and life roles are dynamic and changing over time, depending on their age and context (McKenna, Liddle, Brown, Lee et al., 2009).

Stroke has conventionally been viewed as affecting the population over the age of 65 years (Krishnamurthi, Feigin, Forouzanfar, Mohammad et al., 2013), who are in their mature or late adulthood life stage (Armstrong, 2007). Within these life stages, people are less active with regards to employment and household responsibilities and therefore these types of role responsibilities and activity requirements were not a priority in rehabilitation and healthcare services. This study contributes to the literature by highlighting how younger age at the time of stroke places greater demands on individuals to continue fulfilling different life roles, including responsibilities within their family and household, other than just the role of self-care.

In this study, the younger participants were expected to be economically active to provide for their households and other dependants. Before the stroke, most study participants were involved in income generating activities and were providing for their households, but after the stroke most of the women were unable to return to work and were dependant on government social grants. The study findings concur with (Rouillard, De Weerd, De Wit & Jelsma, 2012)

who found that young participants with stroke were expected to be economically active and had to support other dependants.

In this study the overwhelming majority of participants were main caregivers of young children irrespective of their marital status or age. It was only the older women with stroke whose children were adults and lived in a different area who reported that they did not have to care for them. However, some older women had the responsibility of looking after their grandchildren, especially in rural areas. This could be attributed to younger people migrating to urban areas looking for work, as well as the high mortality rate of young adults associated with the HIV epidemic (Phetlhu & Watson, 2014:348; Tollman, Kahn, Sartorius, Collinson et al., 2008).

According to (Armstrong, 2007) a person in early adulthood and midlife needs to go out into the world to make a mark for themselves. They must be able to mobilise into their communities to develop friendship, meet partners and further their major life roles. Even within the mature adulthood life stage people often participate in volunteering work and giving back to their community (Armstrong, 2007). However, following the stroke, the study participants struggled with mobility and accessing transport, while some were dependant on others for basic self-care in the home.

The overall relatively young average age of the participants reflects current trends noted in the literature (Connor, Walker, Modi & Warlow, 2007; Karbasi-Afshar & Izadi, 2014; Kissela et al., 2012; Russell, 2010). Given this transition in the population suffering from stroke, it is essential to determine the roles and activity requirements that are relevant to a younger population with strokes, in order to contextualise healthcare services to address their healthcare and rehabilitation needs. This study found that women with stroke who are within a younger life stage will struggle not only to care for themselves, but struggle to be a caregiver for their children, provide for their households and re-integrate into their communities.

5.3 The relationship between environmental factors and activity requirements to fulfil role responsibilities

The life roles of a Xhosa woman emerging from the data included self-care, provider, caregiver and community member. These were found to be similar for urban and rural participants. These life roles were seen by participants as relating strongly to their Xhosa cultural identity, and within this their gender.

In the literature on participation in life roles following stroke, similar valued roles were described to those identified by this study participants, including caregiver and home maintainer roles (McKenna et al., 2009) and social as well as employment activities (Rhoda, 2012; Robison, Wiles, Ellis-Hill, McPherson et al., 2009; Wasserman, de Villiers & Bryer, 2009). However, no research has been found to describe specific activity and task requirements for these roles, or the ways in which context shapes participation. This study addresses this gap in the literature with respect to rural and urban Xhosa women in South Africa.

In the following section the different life roles and responsibilities of participants are discussed, starting with the basic role of self-care and moving to more complex roles such as provider, caregiver and community member. Complementary data from the D&E questionnaire and quantitative data from the Barthel Index and EQ-5D are compared with the qualitative findings in order to answer the research question on the activity requirements for fulfilling the life roles of Xhosa women in rural and urban settings.

5.3.1 Self-care

Many frameworks for the assessment of function and participation view self-care (including looking after one's health) as merely a requirement for the fulfilment of social roles (Gosmanhedstro & Blomstrand, 2008; Rouillard et al., 2012).

Self-care requires that people understand their social identity and its related expectations, as well as the activities required to fulfil these. Many people take the role of looking after themselves for granted. However, people with stroke need to strategise and be able to adapt to their limitations and context to look after themselves. Being able to exercise autonomy and experience self-efficacy is also considered important for individual's wellbeing (Horne, Lincoln, Preston & Logan, 2014).

In addition to performing activities of daily living such as dressing and bathing, self-care for the participants included taking care of their own health. Given the ongoing health conditions which led to their strokes, this was a particularly important responsibility.

It is for these reasons that the researcher views self-care as a separate life role with different role responsibilities and activity requirements from that of other life roles such as provider, caregiver and community member. In the following sections, the different activities and task

requirements of fulfilling the self-care role within the participants' context are discussed. The significance of environment in shaping these role requirements is highlighted.

5.3.1.1 Mobility

Walking and carrying water inside the home was an integral task requirement for the activity of bathing. In the EQ-5D, over half of the participants in both settings reported moderate to severe problems with mobility. This contradicts the findings of the BI, in which over two thirds of the study population reported that they were either independent or needed minimal assistance with mobility. The contradictory findings can be explained by the validity of each outcome measure. The BI assesses mobility over an even terrain, while the EQ-5D measures functional mobility within the participants' context. A large majority of rural participants felt they would be able to walk 50 meters on even terrain, but within the rural setting the surroundings were seldom even and activities required participants to walk far distances over rough and uneven terrain.

The overlap of different data sources in this study highlights the limitations of the BI in assessing functional mobility. The assessment of mobility in the BI cannot be generalised to assess functional mobility skills, as often participants do not have even terrain to walk over, and other tasks such as carrying water must be performed while walking.

Functional mobility was not only a requirement to perform other activities, but essential in the safety and survival of participants in rural and urban settings.

In the urban setting participants expressed fear for their lives if something happened in their home and community, such as a fire, as they would not be able to flee to safety. Fires in Cape Town's low income areas are a great risk especially during winter months, due to high population density and the use of open flame cooking fuel, such as gas or paraffin (Smit, De Lannoy, Dover, Lambert et al., 2015). These dangers contributed to participants' anxiety in urban settings, as presented by the EQ-5D, especially when they had mobility difficulties. The participants' fear of fire not only highlighted the importance of functional mobility skills in performing activities, but functional mobility as a vital requirement for a person's survival after a stroke.

Two case series studies done on people with stroke in rural parts of Africa found that at follow-up, a large majority of participants had passed away (Jones, Howitt, Jusabani, William et al., 2012; Wasserman et al., 2009). According to Wasserman et al. (2012) the survivors in

the study showed improvements in walking, transfers and going to the toilet, as compared to when they were discharged from hospital. This highlights the importance of mobility skills and the ability to perform basic activities of daily life, such as toileting, in reducing the mortality risk.

The mobility requirements associated with activities of daily living described in this study, concur with (Rhoda, 2012) who reported mobility limitations were the most common factor hindering independence in activities of daily living for people with stroke. However, the study did not report on the mobility requirements within the participants' context. Balasubramanian, Clark & Fox (2014) stated that despite the relevance of functional walking, the assessment of walking adaptability in relation to environmental and task demands has received little attention in current research. The findings of this study address that gap by giving a rich in-depth description, using several data sources, of the mobility demands for women with stroke of different role responsibilities and activity requirements in rural and urban settings.

Mobility assistive devices such as wheelchairs could also aid in functional mobility and performing activities of daily living. An appropriate wheelchair highlights the interaction between product and technology and the natural environment, enabling the user to mobilise functionally within their context, perform activities and fulfil roles (Visagie, Scheffler, & Schneider, 2013). If the participants' wheelchairs were not suited to the environment, they experienced barriers in functional mobility, and had to hire private transportation and be dependent on others to assist them over rough terrain.

The environment outside of the women with stroke's homes differed completely in each study site. As observed by the researcher during time spent in each setting, the terrain around rural participants' homes was uneven, consisting of grass and narrow footpaths. In the urban site, terrain was mainly flat, with sandy areas between the dwellings and tar roads. Participants in the two areas would require different types of wheelchairs to assist their functional mobility both within their home and within their communities.

Urban participants found it difficult to mobilise with their wheelchairs through the sand in front of their homes. Similar experiences were reported by (Cawood & Visagie, 2015) where participants struggled to mobilise through sand and rough terrain with their wheelchairs. According to Visagie, Duffield & Unger (2015) the inappropriate prescription of wheelchairs negatively affects the function of the person and durability of the device. Such devices are

then inappropriate to use, break easily and restrict the users' mobility and participation even further.

It would be expected that rural participants would express similar if not more barriers to community mobility, due to inappropriate wheelchairs as reported by Vergunst, Swartz, Mji, MacLachlan et al. (2015). It must be highlighted that participants were not directly asked about barriers with the use of wheelchairs, but rather just about their ability to mobilise inside and outside of their homes. None of the rural women with stroke described any barriers experienced with using their wheelchairs. This can be explained by the low percentage of rural participants who had and used a wheelchair at all. As terrain is generally very rough in the rural setting, inappropriate wheelchairs create a bigger barrier to community mobility. Participants are thus required to be able to walk outside their homes otherwise community re-integration is limited leading to social isolation.

5.3.1.2 Bathing and toileting

In both urban and rural settings, self-care included activities such as bathing and toileting. The task requirements for these activities were strongly shaped by environmental factors such as the availability of water and sanitation services within participants' dwellings, and the natural environment outside their dwellings. If participants did not have access to basic services, the consequences were often additional physical task requirements in order to perform self-care activities.

Bathing is often done in a shower or bath tub, however none of the participants reported having access to these facilities, and few participants had access to hot running water. The task requirements for bathing in both settings therefore included boiling water using the cooking fuel available, walking while carrying the hot water to the washing basin, and then washing themselves.

Bathing was described as a problem for a larger percentage of participants in the urban setting compared to the rural setting according to the SSI, the Barthel Index median score for bathing and the EQ-5D score for self-care. This is despite a larger percentage of urban participants being able to access running water inside their homes.

These study findings as described above also translate to the lack of context the BI gives in assessing toileting. Toileting was another activity in which the BI score, which was similar for both settings, did not take account of context and differences in access to sanitation

amenities. The location of the toilet area used by all the rural and some of the urban participants was outside their dwellings. As observed by the researcher during visits to participants' homes, the rural women had to mobilise over uneven ground, grass and narrow pathways to reach the toilet area, while urban participants often had to walk over sand and through narrow passages. This terrain was very seldom level, especially in the rural site where walking outside the dwellings to perform activities often meant long distances up and down hills. The lack of water and sanitation services within their dwellings results in additional task requirements, such as having to mobilise over the rough terrain to reach the toilet facilities. Women with stroke often struggled to perform these additional task requirements which rendered them dependant on others in order to fulfil their self-care roles. These findings demonstrate the limitations of the BI in assessing a person's context and activity requirements associated with activities of daily living, which makes generalisability and comparison of the BI findings problematic between different population groups and settings.

5.3.1.3 Accessing healthcare services

While discussing transportation in the SSI, differences in rural and urban community members' attitudes towards women with stroke arose. It has been documented that taxis often do not want to pick up people with disabilities as it takes longer to get the wheelchairs loaded and these also take up more space (Cawood & Visagie, 2015; Vergunst et al., 2015; Visagie, Duffield & Unger, 2015). However, rural participants expressed that although the larger community does not assist them often, people will occasionally move from the front seat to let them sit there so as to make transfers into the vehicle easier. Participants also reported that they did not have to wait in long queues as they are moved to the front. Women with stroke in rural areas also reported that they are accommodated at community events and meetings. They are offered a chair to sit on instead of sitting on the ground, and at times can relax while others prepare food and drinks.

This contrasts with the findings of a quantitative study by Maart, Eide, Jelsma, Loeb et al. (2007) which assessed environmental barriers experienced by rural and urban people with disability. They found that rural participants reported significantly more barriers associated with community attitudes than the urban group. Despite the large sample size of Maart et al., (2007), the different data sources of this study give a richer description of the participants' experiences relating to their perceived barriers and facilitators of participants in the rural an urban setting. A limitation expressed by Maart et al. (2007) was that study participants did not

comment on any facilitators experienced within their environment, which could be indicate that the participants did not understand the data collection tool completely.

In this study, most of the rural participants reported seeing a physiotherapist at their local healthcare facilities, while none of the urban participants did so. Although some urban participants did report receiving inpatient rehabilitation, none of them saw any allied health practitioners regularly at their local healthcare facilities. This finding could be due to recruitment bias as the NGO who assisted in the study in the rural setting was running a community based rehabilitation project, training mid-level rehabilitation workers to support persons with disabilities in their homes and community. These workers receive referrals from the local hospital's physiotherapist and occupational therapist. The potential participants approached had previous contact with rehabilitation services at the hospital and some at clinics, as reported in the D&E questionnaire. This specific finding of rural participants' regular access to physiotherapy cannot be generalised to similar populations in other rural settings.

In summary, within the self-care role the task requirements to perform activities were shaped by environmental factors within participants' dwellings and in the natural environment outside. Within this role, the activities and task requirements were similar in the rural and urban study sites, but differed from the Western norm in relation to bathing and toileting. This study's findings add depth and context to the understanding of the activity and task requirements for Xhosa women with stroke to fulfil their self-care roles within the infrastructure and services available within their environment.

The ability to functionally mobilise in and outside of the participants' dwellings is essential for independence within the self-care role. Mobility is essential for survival and mobility assistive devices were often inappropriate for the participants' context. The rich description of the context of these clients assists with identifying the mobility requirements to perform activities and re-integrate into their communities.

Within this section the overlap of different data collection tools not only adds to the validity of the findings, but also to the depth and richness of the description of participants' context and roles requirements. However, the overlap of these tools also highlights the limitations of the BI's ability to give context to its findings.

5.3.2 Provider

The dependence ratio classifies the economically dependent population as under the age of 15 and over the age of 65 years (Statistics South Africa, 2013). The rest of the population are expected to be economically active and provide for themselves and their household. In this study, only two rural (18.2%) and one urban participant (11.1%) fell in the dependence age group. Women in rural and urban settings expressed the importance of fulfilling their life role as a provider not only for themselves, but for their families and households. The responsibilities within this role were providing shelter, home maintenance, acquisition of goods and generating an income through employment.

It was within this role that large disparities appeared between the activity requirements in rural and urban settings. The largest disparities in activity requirements were within the role responsibilities of providing shelter and home maintenance, and acquisition of goods. Environmental factors, including products and technology, services and the natural environment, shaped the activities and tasks associated with the role of provider in the rural and urban settings.

5.3.2.1 Providing shelter and home maintenance

In rural areas, the Xhosa people have used the resources available in their natural environment to build and maintain shelter for many years. While some modern materials such as cement are sometimes used, these merely affect the durability of the structures, not the traditional methods of construction and maintenance. Despite the physical demands of these activities, participants in both settings reflected on how they valued this cultural knowledge and took pride in performing the meaningful activities associated with providing shelter and decorating their houses.

In Xhosa culture, women are often responsible for the completion of physical activities and task requirements. Before the stroke, rural participants were able to carry out these tasks themselves, using freely available natural resources, and this responsibility therefore carried few financial costs. In the urban setting, access to natural resources for building is more limited and participants had to buy materials and products and pay skilled services to complete the work. This added financial costs for participants living in an urban area.

After stroke, many rural participants were unable to perform the meaningful activities associated with home maintenance due to limitations in functional mobility and bilateral hand

use. These responsibilities were often transferred to other family members. However, where family support was inadequate, participants would have to pay someone to assist them. At times, financial restrictions meant these role responsibilities were often not carried out in a household, which related to loss of self-worth and identity.

5.3.2.2 Acquisition of water and food

The responsibilities relating to the acquisition of goods entailed providing water and cooking fuel and sourcing food. The activity requirements to fulfil these roles and responsibilities showed some differences between rural and urban participants.

As previously discussed, limited access to water services within the participants' dwellings meant that additional tasks and activities were required to procure water. In the rural setting participants had to rely on natural water resources, such as rivers, of which the quality was very poor. The lack of accessible safe drinking water increases the possible risk of contracting infectious diseases, which impacts on the health of rural women with stroke.

Women with stroke struggled to collect water in both rural and urban settings as they struggled to place the filled bucket on their heads and balance it while mobilising over rough terrain.

Subsistence farming is a characteristic of rural areas (National Treasury, 2011; Neves & Toit, 2013). This is reflected in the findings of this study as all the rural participants grew their own vegetables which they cooked. This was also viewed as a meaningful and enjoyable activity by these women. Even urban participants who had migrated from a rural area reflected on gardening and how much they enjoyed it. After the stroke, the women struggled to participate in this activity, as gardening required bilateral hand use and functional mobility. In the rural setting, the responsibility of gardening and growing vegetables fell onto other family members. However, if social support was restricted, participants were also required to buy more food for cooking. This placed an additional financial burden on women with stroke, who were unable to return to work and generate an income.

Before the stroke, urban participants were more reliant on buying food, as natural resources, space and time were limited to grow their own vegetables. Women often were responsible for shopping for food for their households. As all participants were dependent on government grants following their stroke, it can be speculated that they had to choose cheaper food options which may be easier to prepare, but often lack nutritional value and are high in fat and

sugar (Steyn, Jaffer, Nel, Levitt et al., 2016). This would have health implications for women with stroke and their families as such cheaper food options could contribute to further chronic disease.

5.3.2.3 Employment

The majority of women in both study sites were previously employed as domestic workers in other people's homes. They expressed that they would struggle to return to work, as they are unable to cook and clean properly in their own homes, let alone to their employers' standards. All of the participants were unable to return to work and were financially dependent on government disability grants or pensions which were less than what they had previously earned. This finding links with Hassan, Visagie & Mji, (2012) who found that in South Africa, people with stroke have limited success in returning to productive activities such as generating an income. This places an additional burden on households where the woman with stroke was previously a main breadwinner.

Government grants are a facilitator for women with stroke in procuring basic goods, but many struggled to buy the things they and their family needed with the limited grant money. Especially in urban areas, participants expressed the stress and anxiety related to living on a grant that was much less than their previous income. The financial stressors described by the urban participants influenced their scores on the EQ-5D's health state dimension of anxiety and depression, which were higher than the rural participants'.

The higher perceived anxiety and financial stressors among urban women with stroke corresponds with a study by (Maleka, Stewart & Hale, 2012:25), which found that the inability to return to work appeared to be a bigger problem for urban residents, as they had to pay rent on their homes and had more expenses. However, many rural participants also expressed distress at not working, and incurred additional expenses by paying others for manual tasks they are unable to complete.

In both rural and urban settings, participants reported greater expenses in the areas of housing and acquisition of food following the stroke. Family support could reduce this burden where others were able to take on some of the activities, but in the absence of this, certain responsibilities could no longer be carried out, resulting in a loss of self-worth and reduced HRQoL.

5.3.3 Caregiver

Looking after children was a responsibility highlighted by an overwhelming majority of participants in both rural and urban settings. The role responsibilities for looking after children entailed activity requirements such as preparing meals and household chores such as laundry. As the rural group was mainly within early adulthood and midlife, they often had young children under the age of 6 years to care for. This age group of children are very dependent on carers for feeding, bathing and dressing. Despite participants in both settings struggling with some of these self-care activities themselves, they also had to perform them for younger children.

In the rural setting, where there were often fewer adults present at home, children actually needed to take care of the family member with stroke, whereas in the urban setting the caregiver role was most often taken on by other adult family members. This situation was briefly mentioned by Cawood & Visagie (2015) who described the burden placed on a 14-year-old child, who had to take time off school to collect medication from the clinic for a woman with stroke. Although research has been done on the strain and burden experienced by adult caregivers of people with stroke, limited literature could be found which addressed the impact on younger children of looking after parents with stroke.

This aspect of the study has implications for the quality of support experienced by participants in the home, but also for the possible consequences for children and their development in such situations. With the increased incidence of younger stroke (Maredza, Bertram & Tollman, 2015) this is a phenomenon that will only become more common.

5.3.3.1 Preparing a meal and cooking

One of the role responsibilities included in looking after children and other family members in both settings entailed preparing and cooking food. This study demonstrated differences in food preparation activities and task requirements in rural and urban contexts. Rural women had additional tasks associated with preparation of the fresh produce they grew to eat, while urban participants tended to buy ready processed food such as maize meal. This may explain the Barthel Index scores for the activity of feeding, which indicated that the majority of rural participants needed assistance with this, while most urban participants were independent.

In the rural setting, additional tasks associated with preparing food were often done sitting on the floor. Rural women described a more outdoor lifestyle and would often sit on the ground

outside. Both rural and urban participants said that they enjoyed sitting on the floor on traditional Xhosa mats to stretch their legs. The Barthel Index measures independence in transfers, described as moving from bed to chair, however many rural households had limited furniture, and beds were often mattresses on the ground. For this reason, transfers to and from the ground were included in the self-reported assessment of transfers within the BI. The BI scores reflected that most rural participants needed assistance with transfers, while urban participants were mostly independent. It could be conjectured that rural women with stroke did not view transfers as simply being from bed to chair, but also to their usual/accustomed sitting position on the floor. These transfers were a cultural norm, and part of daily domestic activities such as food preparation.

This further highlights the limitations of comparing BI scores across different cultures and settings. The task requirements for activities listed in the BI can differ depending on cultural or environmental factors.

5.3.3.2 Laundry

As seen with other activities, doing laundry is also shaped by environmental factors relating to services such as water and electricity. Rural participants had additional tasks relating to laundry due to the lack of running water and access to electrical appliances such as washing machines. As laundry requires a large amount of water and water sources were far from rural participants' homes, they had to walk to the river with their laundry to wash them.

This study demonstrates how the lack of municipal services such as running water inside the home, and cultural norms related to preparing food, shape the activities required to fulfil Xhosa women's role responsibilities as a care-giver.

5.3.4 Community Member

The role of community member entailed different role responsibilities, such as being a church member, and participating in social events and community meetings. The activities required to fulfil these roles often included mobilising in the community and accessing transportation. In the D&E questionnaire women in both settings reported reduced participation in community activities. In the SSI, participants expressed that they felt isolated from their communities. Community mobility and transportation were most often identified as contributing to their social isolation.

Rural participants used to walk in their community not only to complete household tasks, but to attend church or community meetings. Urban participants more often accessed to public transport for community activities.

Despite the described experiences of social isolation, some participants who could not attend events had religious groups come to visit them at home, and community members relaying information to them from community meetings. This gave participants not only an ongoing sense of belonging within their community, but also gave them hope.

Religion plays an important role for people with stroke, as they may draw on their spirituality for/as a source of hope (Maleka, Stewart & Hale, 2012:25). A Muslim participant in a qualitative study by Norris, Allotey & Barrett (2012) in Indonesia described the importance of religion in their everyday life by stating:

“As normal people, first we pray, second we do work, third we do normal action, free to go anywhere. That is being healthy.”

Despite the different location and religion represented in this study, the finding resonates with our participants’ experience of the importance of continuing with religious activities despite their limitations.

Findings in this study however give limited insight into how the activity requirements of being a community member compare for Xhosa women with stroke in rural and urban contexts.

5.3.5 Summary

In this chapter the activity requirements to fulfil the roles of Xhosa women in rural and urban areas are compared and discussed. As the participants were from the same cultural group, some activity requirements were similar in both settings, such as sitting on the floor while performing some activities, and carrying heavy objects on their heads.

Different environmental factors shaped certain examples of these activity and task requirements. Many tasks and activities requirements did not only differ from Western norms, but also between rural and urban settings. Within the life roles of provider and care-giver, many activity requirements were influenced by environmental factors. Large disparities existed in the activity requirements for providing and maintaining shelter, acquisition of goods, preparing meals and doing laundry. These disparities add depth and context which echo the

findings of Ali & Mulley (1998), who demonstrated the limitations of the BI in comparing populations from different cultural groups and settings.

After the stroke, participants found themselves dependant on others and needing help with activities within their different roles. One of the key findings of this study was the burden of caring for women with stroke which falls on younger children, especially in rural areas and with a younger population with stroke.

5.4 The activity and participation experiences in relation to participants' life roles

The following section focuses on the personal experiences of participants following a stroke, highlighting the role of social support role fulfilment and health-related quality of life.

The emerging themes from the SSI reflect the different personal experiences of women living with stroke as they struggle to participate in their life roles, as well as their experiences of support structures within the household. The themes that emerged were similar across rural and urban settings, but different between participants. This reflected the findings of Maart et al. (2007) who found no significant differences in perceived support and relationships between people with disabilities from rural and urban areas.

The participants' functional abilities as measured by the BI did not demonstrate a correlation with the EQ-5D HRQoL score as assessed by the VAS. This relates with other literature which has found that functional abilities are not the salient influencing factor in the quality of life of people with stroke (Anderson & Whitfield, 2011; Jones et al., 2012).

Some quantitative research with people with stroke has shown a correlation between motor and functional abilities and perceived HRQoL (Baseman, Fisher, Ward & Bhattacharya, 2010; Chang, Sohn, Lee, Kim et al., 2016; Laurent, De Sèze, Delleci, Koleček et al., 2011; Singhpoo, Charemtanyarak, Ngamroop, Hadee et al., 2016). However quantitative studies give little opportunity if any for research participants to share their experiences of the situation (Rhoda, 2014). Qualitative and mixed methods research are able to give more insight into the experiences of people with stroke with regards to their HRQoL, including contextual factors such as social support, personal confidence in completing activities and participation in valued roles.

The themes that emerged from the qualitative data have a strong link to the participants' perceived social support, their ability to participate in meaningful activities and their

confidence and motivation to fulfil their roles. Complementary data from the BI, EQ-5D and D&E questionnaire was triangulated with each theme, as described in section 4.8.4.3 table 4-3.

5.4.1 Theme 1 – “I struggle with nothing, they do so much for me”.

In theme 1, participants expressed that they no longer participate in many activities around the home or community. Despite this, they reported that they do not struggle with anything either. Participants within this theme had comprehensive social support, which meant that the responsibilities they had to fulfil were now carried by other family members. The EQ-5D scores for this group were higher than for participants in the other themes. This suggests that social support and being able to transfer the responsibilities of their life roles to other family members allowed participants still to experienced self-worth and fulfilment in life. Participants felt taken care of but still felt part of the family.

This contradicts previously held notions that a person with stroke’s quality of life is influenced mainly by their functional independence (Laurent, et al., 2011) and that a person must actively perform meaningful tasks to add value to their lives (Anderson & Whitfield, 2011). However, the findings within this theme suggest that women in this culture who are in late adulthood life stage are content with being taken care of and transferring their valued life roles to others.

Within this theme there was a strong reference to role reversal by the participants as they passed on their life roles and responsibilities to other members of the family, who had to become the caregivers and providers. However, the participants still retained their ascribed status or identity within the family as daughters or wives. They only experienced a loss of control and autonomy in choosing what they wanted to eat and where they wanted to go, as they were inherently dependant on family members. This correlates with (McKenna et al., 2009) who found that people with stroke often relinquished roles that were less important to them but maintained more valuable roles, thereby improving their overall quality of life.

The participants underwent a transformation as they accepted their limited abilities and dependence on others to fulfil household roles. Pundik, Holcomb, McCabe & Daly (2012) describes this as the ‘transformative learning’ process, which is triggered by the realisation of their physical limitations and loss of control. At the same time, they also realise their new capabilities and roles within the household (Pundik et al., 2012). This transformation is

facilitated by family support and education on the illness facilitating changes in the participants' perspective on their quality of life.

Perceptions of the degree of family support were important in order for the participants to be satisfied with relinquishing their roles and autonomy. The women needed to be able to trust that their family would continue to care for them and support the household. During categorisation of participants within the different themes, one woman overlapped between themes one and three (Dead but alive). The participant reported that she did not do much at home and experienced very little support, however through follow-up questions she did describe the role her son and daughter-in-law played in assisting with activities of daily living and household responsibilities. She however perceived their assistance to be lacking and insufficient to her standards. It was for this reason that she was ultimately classified in theme three.

The findings in this theme suggest that functional independence does not necessarily play a critical role in HRQoL for Xhosa women in the late adulthood life stage, but that participants were satisfied to be cared for by their family. This theme also highlights the importance of the women with stroke's perception of adequate family and social support for their HRQoL and their satisfaction with relinquishing their role responsibilities and autonomy.

5.4.2 Theme 2 – “I still like looking smart”

Within this theme, participants have a slightly higher functional ability as indicated by their total BI. For this reason, they are able to take on some their life role responsibilities. Participants however still need assistance to fulfil all roles. They showed the ability to think of and implement different strategies and adaptations in required activities to fulfil their roles. This links with findings from (Jellema, Sande, Hees, Zajec et al, 2016) who found that despite difficult contextual factors faced by people with stroke, they were constantly strategizing to complete the activities. Robison et al. (2009) also stated the importance of adaptability of a person within their environment to resume valued activities.

In this theme the median age of the participants was younger, categorised between young adults and midlife, as compared to participants categorised in the other themes who are categorised in late adulthood. Within these life stages women have more roles and role responsibilities compared to women in late adulthood. Participants classified as young people with strokes were often responsible to look after younger dependent children. This can be an

additional drive to become more independent as participants must not only care for themselves, but care for their children.

A large majority of these young women with stroke disclosed their HIV positive status. According to Benjamin, Bryer, Emsley, Khoo et al., (2012) stroke relating to HIV appears to be much younger and recovery can be much faster as compared to older people. This links with the higher median scores of the total Barthel Index within this theme. The improved recovery since the incidence of stroke may have given these participants hope that they can be more independent and continue with their life roles. Participants within this theme demonstrated a confidence in some of their abilities and were motivated to improve their independence and function. According to Horne et al. (2014) as soon as people with stroke master certain skills, their belief and confidence within themselves grew.

According to (Hassan, Visagie & Mji, 2012) a person with limited abilities does not have to be independent in doing a task, but rather be able to direct caregivers to assist in performing the tasks so as to fulfil the desired activity requirements and role responsibilities. Despite the participants' confidence in some activities they still needed assistance to complete task and activity requirements to fulfil role responsibilities. Many of the participants had to pay for assistance to complete the activities, while others could delegate to family members. This theme differs from theme one in that participants do not relinquish their role or autonomy, but rather strategize solutions to fulfil role responsibilities by delegating activity requirements to fulfil these responsibilities.

While categorising participants in different themes one participant overlapped between theme one and two. She was a young participant who had the role of being a caregiver and provider to her to her young child. As a care-giver she struggled to fulfil the role responsibility of looking after the children by struggling to hold the baby when she cried. This activity was transferred to her mother. However, as a provider she would strategise to access transport to get to her to the clinic to get her medication and shops to buy goods. At times, she would even crawl when walking to the transport if she feared falling over rough terrain.

This theme highlights that despite having the opportunities to relinquish roles some participants' choice to maintain their roles and autonomy. This was especially evident in a younger population.

5.4.3 Theme 3 - Dead but alive.

Within this theme, participants expressed a perceived loss of roles impacting negatively on their life satisfaction and quality of life. They experienced poor social support which hindered their ability to relinquish role responsibilities to other family members.

Rural participants could no longer perform meaningful activities which had cultural value, such as smearing their homes and making traditional beer, and due to inadequate family support the related roles were lost. Participants in urban areas struggled to afford the things they needed with their government grants, and other family members did not fulfil their new roles as providers for the household placing additional financial stressors on the women with stroke.

Several authors noted how loss of roles for people with stroke and other disabilities negatively influences their emotional well-being and perceived HRQoL (Anderson & Whitfield, 2011; Maleka, Stewart & Hale, 2012; Rhoda, 2014; Wasserman et al., 2009). This concurs with the finding that participants within this theme had a lower EQ-5D VAS score than those categorised in the other themes.

All of these participants lost some activities, particularly those they found most meaningful. Women in rural areas had enjoyed decorating their homes by smearing the walls and floors as well as going to church and participating in social groups. Urban participants enjoyed going out with friends and being able to buy nice things for their homes. However, with the onset of the stroke all of these things came to a standstill. Wasserman et al. (2009) stated that high dependency levels of people with stroke and poor family support predict poor outcomes in participation in activities.

Theme three has the opposite attributes to the previous themes. Whereas participants in theme one perceived themselves as having sufficient social support, these women did not. Whereas participants in theme two had the inherent drive to maintain role responsibilities and strategize for solutions, participants in this theme did not and experienced a loss of hope. These study findings concur with Maleka, Stewart & Hale (2012) and Anderson & Whitfield (2011) who found that the loss of hope, including a loss of identity, are often experienced post stroke and can lead to depression. These experiences contribute to participants' poor self-efficacy and self-esteem, where they believe they can't do anything (Horne et al., 2014). This study's findings however give a deeper contextual description of the participants' perceived

loss of hope and factors associated with it. The prevalence of depression in stroke has been associated with the loss of functional abilities. However, this study highlights the interplay between lack of social support and limited functional abilities in contributing to loss of hope resulting in a possible lack of motivation to strategize to overcome barriers to performing activities.

Further, the findings in this theme give context to insight into the interplay between the two parts of the ICF, namely functioning and disability and contextual factors, as they contribute to the decreased HRQoL of these women with stroke. HRQoL.

5.5 Conclusion

This study gives a personal snapshot of women who suffered a stroke in rural and urban environments, describing their perceived activity and participation experiences in fulfilling their life roles. Before the stroke, the women in both rural and urban settings had similar life roles to fulfil in their context, such as looking after themselves, providing and caring for their families and participating as community members.

Within this study the influence of contextual factors on the women's ability and motivation to fulfil their roles is highlighted. Environmental factors shape the activities and tasks required to fulfil their roles. Social support influences participants' life satisfaction, which directly relates to their ability to continue with meaningful activities while relinquishing other role responsibilities. Participants' personal perceptions, confidence and ability to strategize new ways of overcoming barriers to participation improve their independence.

This study highlights the health transition experienced in South Africa which results in an increase of young people with strokes. Understanding the needs of this group, understanding their roles and assessing their contextual factors are all integral in addressing their health-related quality of life. This study also highlights the burden placed by stroke on young children, who themselves are still dependent but may have to take care of their parents and households.

6 Study Recommendations, Limitations and Conclusion

6.1 Introduction

In this chapter, recommendations are made from the study findings for future research and practice. The limitations of this study are also described to assist future researchers in improving the quality of their studies.

6.2 Study recommendations

The study recommendations relate to the key findings concerning stroke in a younger population, the young children who have to care for their parents with stroke, limitations of standardised outcome measures in these study settings and the conceptual framework developed to address the criticisms of the currently used framework.

6.2.1 Implications for health and rehabilitation services

A key finding of this study was the prevalence of stroke among people in their young adulthood and midlife life stages. The study findings align with current literature on the increased prevalence of young people with strokes, especially in the rural setting. The prevalence of young people with strokes, along with their relatively low mortality rate, places additional burden on healthcare services due to their ongoing need for follow-up during their life time. The recommendations of this study relate to stroke prevention, rehabilitation and family support.

According to Krishnamurthi, et al. (2013) high-income countries have shown a reduction in the incidence of stroke as a result of improving their prevention strategies and management of chronic disease. In order to address the increased incidence of stroke and cardiovascular disease in developing countries such as South Africa, it is vital that prevention strategies form an integral part of health care systems. Policies need to be aligned to support the implementation and management of these systems.

This study's findings concur with current literature which states that the increased incidence of stroke and young people with strokes is associated with the increase of non-communicable diseases such as hypertension, in parallel with communicable diseases such as HIV (Defo, 2014; Ntsekhe & Damasceno, 2013). In South Africa, healthcare policies, systems and services need to be aligned to implement appropriate prevention strategies for both

communicable and non-communicable disease. Primary health care systems within these low socio-economic settings in South Africa should support prevention and promotion of a healthy lifestyle by raising awareness on prevention of stroke and managing cardio-vascular risk factors such as hypertension. Stroke prevention strategies need to be expanded and developed to ensure that they include a younger population, in order to decrease the incidence of stroke and prevent lifelong burden of disability (Giroud, Jacquin & Béjot, 2014). Appropriate education needs to be focused on a younger population, particularly with regard to HIV prevention and management. This study indicates a need for further research to understand the contextual factors associated with the rise in these cardiovascular risk factors in South Africa, and especially in a younger population.

6.2.1.1 Rehabilitation services at community level

The study found that for young people with strokes, being economically active, providing for their households, caring for their families (especially children), and being active members of their community were roles that were both required of and meaningful to them. Given the lower mortality rates associated with young people with strokes (Martinsen, Kirkevold & Sveen, 2015) these participants face many years of life with the consequences of stroke, which not only impacts negatively on their participation in life roles and health related quality of life, but also on the wellbeing of their families.

Following a stroke, rehabilitation should follow a continuous progression, starting with basic outcomes such as self-care and building towards more advanced outcomes such as caring for family members and community re-integration (Hassan, Visagie & Mji, 2012). It is important to adapt rehabilitation programs for young people with stroke to facilitate participation in life roles and meaningful activities that are relevant to their life stage. Stroke rehabilitation has traditionally focused on improvement of independence in basic activities of daily living and mobility and has not necessarily placed value on activities at a higher functional level (Robison, Wiles, Ellis-Hill, McPherson et al., 2009). Without contextualised out-patient rehabilitation and ongoing rehabilitation and support at community level, women with stroke often remain dependant on others to complete even basic activities of daily living. Rehabilitation should shift its focus from basic activities of daily living to facilitating the re-integration of women with stroke into community and society where they can actively participate in not only their own development, but also that of their communities.

The findings of this study highlighted the impact of the context in which a person with stroke resides on shaping the activity requirements associated with their role responsibilities. These findings emphasise the importance of rehabilitation and support at community level in contextualising and addressing the needs of a person with stroke.

Limited community based rehabilitation services were available at both study sites, where the burden of providing these services falls on NGOs, who assist with the management and support of people with stroke and other disabilities in the community. It is recommended that government funded rehabilitation and support services be implemented at community level.

6.2.1.2 Family support

The study demonstrated the far-reaching effect of stroke on the individual and her family. Rehabilitation and support services for women with stroke should be multifaceted and both client- and family-centred, in order to reduce the burden placed by stroke on households and communities.

The findings of this study suggest that a person with stroke's perception of social and family support can have a significant influence on their HRQoL. When participants experienced adequate family support, they were able to relinquish their role responsibilities to others while still reporting a relatively high HRQoL. However, where participants experienced poor social and family support, this had a negative effect on their HRQoL. Further research is needed into appropriate service delivery strategies to support and empower families in caring for family members with stroke, but also to develop appropriate community-based services for the social support of people with stroke who lack family support.

Another key finding of this study is the number of young children caring for parents with stroke. These young children had become the primary care-givers of women with stroke while they themselves still needed guidance and caring. It is recommended that future research and discussion focus on establishing appropriate and ethical solutions to address this problem. The effect on the wellbeing of these children also needs to be assessed in terms of the loss of childhood roles and the impact of becoming a caregiver and provider within the household at a young age. There is an urgent need for the development and implementation of systems, policies and services at community level to support these (in effect) child-headed households.

6.2.2 Implications for enabling environments and access to basic services.

In this study, the environmental factors associated with lack of access to products and technology and municipal services created additional task and activity requirements to fulfil life role responsibilities. For example, where both rural and urban participants did not have access to running water inside their homes, they had to mobilise often long distances over rough terrain to fetch water for self-care and household activities as well as drinking. They then had to carry the heavy load back to their dwellings.

Women with stroke were often unable to perform these tasks, increasing their dependence on others, loss of roles, and additional financial burden as they had to pay others to perform essential activities. All of these factors negatively influenced their perceived HRQoL. The lack of basic services such as access to safe drinking water and sanitation services increases the risk of infectious diseases and secondary complications which can have a negative effect on participants' health and survival.

The complex burden of disease in South Africa is also prolonged due to the socio-economic disparities between different population groups, which contribute to the increase of cardiovascular risk factors related to both non-communicable and communicable diseases, contributing to the rising incidence of stroke (Defo, 2014). Government institutions and other organisations need to address these disparities, beginning with basic education, water and sanitation services for communities in low socio-economic settings, so that people are empowered to manage their own health needs.

The findings of this study offer strong support for the provision of accessible services, especially relating to water and sanitation in order to decrease the environmental barriers faced by women with stroke in caring for themselves and their families.

6.2.3 Implications for future research on stroke and other disabilities

This study used several data sources to give an in-depth description of participants' context, functional abilities and experiences after a stroke. The overlapping of these data sources highlighted limitations of some of the standardised outcome measures, such as assessment of functional mobility in the Barthel Index, in contextualising activities of daily living. The lack of attention to context underpinning this measure limited its accuracy in representing functional independence, and as well as its usefulness in comparing different population groups in different settings. This has important implications for future research intending to

use standardised outcome measures developed in high income countries with population groups in different settings or cultures.

The findings and descriptions of the activity requirements, role responsibilities and different roles in this study could be used in the development of more contextually sensitive outcome measures, for use in LMIC's and other non-western settings. Such outcome measures have an important role to play in the monitoring and evaluation of the effectiveness of healthcare and rehabilitation services.

The in-depth description of the activity requirements to fulfil role responsibilities will also inform more appropriate and contextualised rehabilitation services that address the needs of women with stroke within their environment.

The International classification of functioning, disability and health (ICF) has been criticised for its lack of differentiation between activity and participation (Pettersson, Pettersson & Frisk, 2012; Ravenek, et al. 2013), which makes appropriate assessment and subsequent intervention difficult.

This study conceptualised participation as the life roles and role responsibilities of women with stroke. Activity was conceptualised as the activity and task requirements to fulfil the role responsibilities. This conceptual framework built upon the ICF's activity and participation component, and helped to clarify the relationship between activity and participation for Xhosa women with stroke. This in turn will help in determining the healthcare and rehabilitation needs of women with stroke. The same conceptual framework may well be useful to other researchers, policy makers and clinicians using the ICF, and further research is recommended to develop these ideas further.

6.3 Limitations of the study

This study had several limitations, namely small sample size, possible recruitment bias, and the exclusion of potential participants with communication and cognitive impairments.

6.3.1 Small sample size

The small number of participants recruited at each site and overall restricted the statistical analysis and generalisability of the quantitative findings. The small sample size can be attributed to limited resources available for the research.

The use of semi-structured interviews could also have contributed to the small sample, as individual interviews were time-consuming. Focus groups could have assisted in gathering qualitative data in a more time-efficient manner. However, the individual semi-structured interviews gave rich individual accounts of the experiences of Xhosa women with stroke.

Furthermore, this study found that people with stroke, especially in deep rural areas, struggled with mobility and access to transportation, which could restrict their participation in research where travel to a central point is required. It was for this reason the home visits were conducted to gather data. Future research on people with stroke in low socio-economic settings, especially in rural areas, should bear this in mind, as the barriers which exclude people from participation in society may also exclude their experiences from research.

6.3.2 Type of mixed methodology used

The collection of data using a sequential mixed methods approach allows for one type of data to influence a second type, and ensures a more in-depth understanding and exploration of the first type of data. Within this study, the quantitative data could have been collected first and the preliminary results used to inform the qualitative inquiry guide, to address findings such as the apparent disparities between rural and urban participants' perception of their anxiety and depression. However, in a rural environment the use of a sequential mixed methods approach is restricted as participants struggle to access transportation and participants are wide-spread over rough terrain which makes follow up visits difficult.

6.3.3 Recruitment of potential participants

The use of NGOs to recruit participants contributed to reducing the number of study participants and possibly meant that the study participants were not representative of the bigger population.

6.3.4 Questionnaire

Another limitation was noted in the data management and analysis of the self-developed questionnaire, where open ended questions increased the possible variables in some sections and limited the interpretation of the data. For example, participants were asked what activities they did within the household before and then after the stroke. However, answers were so varied that analysis and interpretation were difficult. It is recommended to have standardised answers in the questionnaire which participants can choose from.

6.3.5 Exclusion of potential participants with communication limitations

One significant limitation of this study was the exclusion of women with stroke who had any communication impairments. Current literature highlights that additional barriers to re-integration are experienced by people with stroke who also have communication impairments (Legg & Penn, 2013). By excluding these potential participants, valuable and relevant insight is lost. It is recommended that future research incorporates the experiences of people with stroke presenting with communication impairments. This will also assist with the conceptualisation and contextualisation of standardised outcome measures which are appropriate for people with stroke presenting with communication impairments.

6.4 Conclusion

This study aimed to describe and compare the activity requirements and participation experiences of Xhosa women in relation to the life roles in rural and urban settings. This study found that life roles and role responsibilities for women in rural and urban settings were similar and identified through the qualitative inquiry component of the study were the self-care role, provider, caregiver and community member. All of these roles had different responsibilities, which were described alongside their associated activities. However due to different environmental factors, the activities required to fulfil these role responsibilities differed between rural and urban settings.

The personal experiences of Xhosa women with stroke were also categorised and described within three distinctly different themes. The participants' participation experiences related to their perception of social and family support or lack thereof and their drive to strategize to perform activity requirements to fulfil their role responsibilities.

This study adopted a novel conceptual framework which defined participation as life roles and their related role responsibilities, while activity was defined as including the task and activity requirements to fulfil these role responsibilities.

The activities and tasks identified from the qualitative inquiry were triangulated with complementary data from the D & E questionnaire, BI and EQ-5D to give a contextually rich description of participants' ability to perform the activities and tasks within their environments. The overlapping of the data did highlight the limitations of the BI in assessing the contextual factors influencing activities of daily living and the ability to compare different populations from different settings and cultures.

The increasing prevalence of stroke in young women should catalyse a paradigm shift in healthcare management and stroke rehabilitation to support individuals and families affected by stroke. Further research is needed to change policies, systems and services to prevent strokes, and improve these women's participation in life roles through an in-depth understanding of activity requirements within their contexts. Future research is also recommended into using its conceptual framework to address the identified limitations of the ICF, and to contextualise appropriate outcome measures for women with stroke in similar settings.

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Appendix 1: Proof of Ethical Clearance by the Stellenbosch University Health Research Ethics Committee (HREC)



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Ethics Letter

09-Dec-2015

Ethics Reference #: S13/08/156

Title: Determining and comparing the activity requirements to participate in life roles: Female Xhosa stroke sufferers in rural and urban environments.

Dear Ms. Marlie Enright,

The HREC approved the following progress report by expedited review process:

Progress Report dated 01/01/2015 - 01/10/2015

The approval of this project is extended for a further year

Approval date: 09 December 2015

Expiry date: 09 December 2016

If you have any queries or need further help, please contact the REC Office 0219389657.

Sincerely,

REC Coordinator
Franklin Weber
Health Research Ethics Committee 1

Appendix 2 Informed Consent Form

INKCUK ACHA ZALOWO UTHATHA INXAXHEBA NEFOMU YESIVUMELWANO
YOPHANDO OLUNGEZIFUNDO ZEMFUZO

ISIHLOKO SEPROJEKTHI YOPHANDO:

Ingcaciso nokudibanisa iimfuneko zokutata inkxaxheba kwimo yemihla ngemihla yempilo kubafazi abaye bachapazeleka kwisifo sokufa icala kwimeko yempilo kwiindawo abahlala kuzo ezidolopini nakumapandle.

INOMBOLO YESALATHISO: S13/08/156

UMPHANDI OYINTLOKO: Marlie Enright, Nobuntu Ngcoyi

IDILESI: Division of Physiotherapy, Faculty of Medicine and Health Sciences, University of Stellenbosch, PO Box 19063, Tygerberg, 7505

CONTACT NUMBER:

021 938 9300 / 082 094 2848 / 061 352 4261

INOMBOLO YOQHAGAMSHELWANO:

Siyakumema ukuba uthathe inkxaxheba kwesi sifundo sophando esibandakanya uhlelo ngezemfundo nokugcinwa kwegazi ixesha elide okanye inyama ezithile esemzimbeni. Nceda uzinike ixesha lokufunda iinkcukacha ezichazwe apha, eziza kucacisa ngeenkcukacha zale projekthi. Nceda ubuze kwabo basebenza ngesi sifundo okanye kugqirha nayiphi na imibuzo nangayo nayiphi na into ngale projekthi ongayiqondiyo ngokupheleleyo. Kubaluleke kakhulu ukuba waneliseke ngokupheleleyo okuqulathwe kolu phando nokuba ungabandakanyeka njani. Kwakhona, ukuthatha kwakho inkxaxheba **akunyanzelekanga uyazikhethela** kwaye ungala ukuthatha inkxaxheba. Ukuba uthi hayi, oku akuzi kukuchaphazela ngendlela embi. Ungarhoxa kwesi sifundo nanini na, nokuba uyavuma ukuthatha inkxaxheba.

Esi sifundo sivunywe **yiKomiti yoPhando ngomntu kwiYunivesithi yaseStellenbosch** kwaye luza kwenziwa ngokwemigaqo yokuziphatha ngokusesikweni evunyiweyo ekuhlaleni nakwamanye amazwe nemithetho-siseko yeSibhengezo saseHelsinki, kunye neMigaqo yaseMzantsi Afrika ka-2004 yeSebe lezeMpilo: *lindlela zokuziphatha kuPhando lwezeMpilo: Imithetho-siseko, Ubume neNkqubo*.

Yintoni uphando lwemfuzo?

- Uphando olu lumalunga nokuvavanya imeko ubani apila kuzo kwindlela aphila ngayo kumapandle nasezidoloipini ,kwiimeko apo owasethyini kwa Xhosa ekulindeleke ukuba athathe inkxaxheba kwiizinto ezijikeleze ikhaya nasekuhlaleni ngokubanzi.
- Isifundo esi siya kuti sitate inkxaxhebo kwabo bahlala kumapandle esitili sase OR Tambo kwiphondo leMpuma koloni nakwii lokishi zase Khayelitsha kwiphondo le Ntshona koloni.Abantu abavumelekileyo ukuthatha inkxaxheba kwisifundo esi bamalunga namashumi asibhozo anesibhozo kwaye isifundo esi singolwimi oluntetho isiXhosa okanye isingesi.
- Udliwano ndlebe olu luya kuthi kusetyenziswe intetho esisiXhosa okanye ulwimi lwasemzini.
- Isifundo esi sigunyazisa ubani ukuba abe nokuphendula udliwano-ndlebe olu oluya kubandakanya iziphumo ezizizo malunga neemeko zokujamelana nonyango sokufa icala: umzekelo EQ -5D nokunye kwi Barthel index.
- Udliwano ndlebe olu luya kucinezelwa phantsi konke okuya kuthi ubani athethe ngako malunga nobunzima aye athi ahlangebezane nabo ekhaya.
- Amagama akuluhlu kwabatata inkxaxheba afunyenwe kwimibuto engeko phantsi kolawulo luka Rulumente.Abanye abantu esinabo kuluhlu ngabacelwe ngokusesikweni ukutata inkxaxheba.

Ingaba kutheni umenyiwe ukuba uthathe inkxaxheba kwisifundo esi?

- Ukuluhlu lwabamenyiweyo ukuthatha inkxaxheba kwisifundo esi njengoko ungowasethyini oye wathi wachaphazeleka kwisifo sokufa icala kwaye uhlala kwingingqi ekhethiweyo ukuthatha inkxaxheba.

Zinto zini ekufuneka uzenzile?

- Uyacelwa ukuba unike inkcazelo esulungekileyo nenyani sekileyo ube unganako ukuba yinkxalenye yeqela labo bachaphazekileyo kwisifo sokufa icala kwiindibano zasekuhlaleni ube nako ukwabelana ngolwazi neemeko othe wahlangabezana nazo ekhaya nasekuhlaleni.

Zinto zini eziya kuthi zibeluncedo kuwe ngokuthatha inkxaxheba kolu phando?

- Akuko nto ingako uza kuyifumana kolu phando kodwa ke uya kube unceda abanye abaninzi kwiindlela eziya kuthi ziveliswe kunyango lwesifo sokufa icala.

Buza kuba yintoni ubungozi obubandakanyekayo kuphando lwezemfuzo?

- Akukho bungozi buya kuthi buvele kubandakanyeko lophando lwesi sifundo.

Ingaba liza kugcinwa ixesha elingakanani kwaye liza kugcinwa phi?

- Zonke iinkcukacha zophando ziya kuba phantsi kolawulo oluqatha kwaye aziyi kuveliswa kuwonke –wonke. Amagama akho awayi kubhalwa phantsi kuba siya kusebenzisa iinombolo kumaxwebhu eenkcukacha. Iinkcukacha ziya kuba sezandleni zomphandi oyintloko nomncedisi wakhe kuphela. Zonke iinkcukaxha eziya kuthi zigcinwe kwikompu yutha ziya kuba phantsi kokhuseleko oluqatha nekuya kuba kumphandi oyintloko kupela onokuthi afikelele kuzo. Akukho zinkcukacha ziya kubhalwa phantsi malunga nezigulane naphantsi kwezipi na iimeko awusayi kwaziwa kwaye ungenakwaziswa nakubani na.

Ingaba wena okanye abaphandi baza kuzuza imali na kolu phando?

- Wonke ubani othatha inkxaxheba akasayi kuhlululwa kodwa ke ukuba kufuneke esebenzise isithuthi esihlawulelwayo umphandi oyintloko uya kuzihlawula iindleko zokukhwelisa.

Ungaqhakamshelana nomphandi oyintloko unkosazana Marlie Enright kwezi nombolo zingezantsi 082 094 2848 okanye umncedisi wakhe unkosazana Nobuntu Ngcoyi kwezi nombolo zilandelayo 061 352 4261. Okanye ningaqhakamshelana neli ziko Health Research Ethics committee at 021 938 9207 ukuba kuko izikhalazo okanye inkcazelo ngokubanzi.

Uya kufumana ikopi malunga nolu lwazi notyikityo olugunyazisiweyo noya kuthi ulugcine kuwe.

Isivumelwano salowo uthatha inkxaxheba

Ngokutyikitya ngezantsi, Mna ndiyavuma ukuthatha inkxaxheba kwisifundo sophando ngezemfuzo esinesi sihloko (Ingcaciso nokudibanisa iimfuneko zokutata inkxaxheba kwimo yemihla ngemihla yempilo kubafazi abaye bachapazeleka kwisifo sokufa icala kwimeko yempilo kwiindawo abahlala kuzo ezidolopini nakumapandle. isifundo ngophando lwesifo sokufa isicala)

Ndiyavuma ukuba:

- Ndizifundile okanye ndizifundelwe ezi nkcukacha nale fomu yesivumelwano kwaye zibhalwe ngolwimi endilwaziyo nendiziva ndikhululekile ukulusebenzisa.
- Ndibenalo ithuba lokubuza imibuzo kwaye yonke imibuzo yam iphendulwe ngendlela eyanelisayo.
- Ndiyakuqonda ukuba ukuthatha kwam inxaxheba kwesi sifundo akunyanzeliswanga ndizikhethela kwaye khang ndifakwe xinezelelo ukuba ndithathe nxaxheba.
- Ndifumene ikopi etyikityiweyo yale fomu yesivumelwano ukuze ndizigcinele.

Ityikitywe (*indawo*) nge-.....(*umhla*).

.....
Ukutyikitya kwalowo uthatha inxaxheba Ukutyikitya kwengqina

Isivumelwano somphandi

Mna (*igama*) ndiyavuma ukuba:

- Ndizicacisile iinkcukacha ezikolu xwebhu ku
- Ndimkhuthazile ukuba abuse imibuzo kwaye athathe ixesha elaneleyo ukuba ayiphendule.
- Ndanelisekile ukuba uyiqonda ngokupheleleyo yonke imiba ekolu phando, njengoko bekuchaziwe ngentla
- Ndiyisebenzisile/andiyisebenzisanga itoliki.

Ityikitywe (*indawo*) nge-(*umhla*) ngo-
 2015

.....
Ukutyikitya komphandi

.....
Ukutyikitya kwengqina

Isivumelwano setoliki

Mna (*igama*) ndiyavuma ukuba:

- Ndimncedisile umphandi (*igama*) ukucacisa
iinkcukacha ezikolu xwebhu (*name of participant*) ku-
..... ndisebenzisa ulwimi
lwesiBhulu/lwesiXhosa.

- Ndanelisekile ukuba lowo uthatha inxaxheba ukuqonda ngokupheleleyo oko kuqulathwe kolu xwebhu lwesivumelwano kwaye yonke imibuzo yakhe iphenduleke ngokwanelisayo.

Ityikitywe (*indawo*) nge-.....(*umhla*) ngo-2015.

.....
Ukutyikitya kwetoliki

.....
Ukutyikitya kwengqina

PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

TITLE OF THE RESEARCH PROJECT:

Determining and comparing the activity requirements to participate in life roles: Female Xhosa stroke sufferers in rural and urban environments

REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: Marlie Enright

ADDRESS:

Division of Physiotherapy, Faculty of Medicine and Health Sciences, University of Stellenbosch, PO Box 19063, Tygerberg, 7505

CONTACT NUMBER:

021 938 9300 / 082 094 2848

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the researcher any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to refuse to take part. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the Health Research Ethics Committee at Stellenbosch University and will be conducted according to the ethical guidelines and principles of the International Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

What is this research study all about?

This study aims to give an deep understanding of how the area where you live affects activities you need to complete, to take part in the life roles of Xhosa women in rural and urban environments.

The study will be done in a rural part of the OR Tambo district in the Eastern Cape and the Khayelitsha district in the Western Cape. Eighty eight participants will be chosen in total for this study.

The survey, outcome measures and focus groups will be conducted in English or Xhosa depending on the home language of the participants.

You will be asked to complete a survey developed for this study and outcome measures used in stroke rehabilitation i.e. EQ-5D and the Barthel Index. You will also be invited to take part in a group discussion in your area to further talk about activities you may have problems with in your home and community.

The names of women who can take part in this study were collected from healthcare institutes and non-government organisations in your area. Only some of the people on the list will be asked to take part in this study.

Why have you been invited to participate?

You have been invited to take part in this study because you are an adult female who suffered a stroke in the last 6 to 18 months and living in the area where the study is conducted.

What will your responsibilities be?

Your responsibility in this study would be to answer all questions truthfully and if possible attend a group meeting to discuss your experiences in your home and community after suffering the stroke.

Will you benefit from taking part in this research?

You will not benefit immediately from taking part in this study, but with your will help to make rehabilitation of other people with a stroke better in the future.

Are there any risks involved in your taking part in this research?

There are no risks involved in participating in this study

If you do not agree to take part, what alternatives do you have?

Taking part in this study is voluntary.

Who will have access to your medical records?

All your information will be treated as private (confidential). Your records will be given a number in this study. Your name will not be written on any of the forms and none of your personal details will be visible. Only the study leader and research assistant will use the forms and information. These will not be shared with other people. All the information will be placed on a computer that will be password protected, that only the researcher will know. Your identity will not be used in any article or thesis written and you will remain unidentified. Information collected from medical records will be kept private.

What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?

There are no risks in taking part in this study and no injury will occur to you.

Will you be paid to take part in this study and are there any costs involved?

There will be no costs involved for you, if you do take part. You will not be paid to take part in the study but any transport costs relating to taking part in the study will be covered by the study researcher.

Is there any thing else that you should know or do?

You can contact Marlie Enright at tel 021 938 9300 if you have any further queries or encounter any problems.

You can contact the Health Research Ethics Committee at 021-938 9207 if you have any concerns or complaints that have not been adequately addressed by your study doctor.

You will receive a copy of this information and consent form for your own records.

Declaration by participant

By signing below, I agree to take part in a research study entitled *(insert title of study)*.

I declare that:

I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.

I have had a chance to ask questions and all my questions have been adequately answered.

I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.

I may choose to leave the study at any time and will not be penalised or prejudiced in any way.

I may be asked to leave the study before it has finished, if the study researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at *(place)* on *(date)* 2013.

Signature of participant

Signature of witness

Declaration by investigator

I *(name)* declare that:

I explained the information in this document to

I encouraged him/her to ask questions and took adequate time to answer them.

I am satisfied that he/she adequately understands all aspects of the research, as discussed above

I did/did not use a interpreter. *(If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) on (*date*) 2013.

Signature of investigator

Signature of witness

Declaration by interpreter

I (*name*) declare that:

I assisted the investigator (*name*) to explain the
information in this document to (*name of participant*)
using the language medium of Afrikaans/Xhosa.

We encouraged him/her to ask questions and took adequate time to answer them.

I conveyed a factually correct version of what was related to me.

I am satisfied that the participant fully understands the content of this informed consent
document and has had all his/her question satisfactorily answered.

Signed at (*place*) on (*date*)

Signature of interpreter

Signature of witness

Appendix 3 Data Collection Procedure Checklist

Data Collection Protocol	Participant Nr:	Done
Introduction	Marlie Enright - Physiotherapist working in Cape Town. Studing at University of Stellenbosch in Master of Physiotherapy. Use to work in setting	
	Nobuntu Ngcoyi - Community Worker in Cape Town. She is the research assistant and translator for this study	
Declaration	We do not work for the Hospital or any NGO. We are just here as part as my study to find out more about the problems you experience after suffering a stroke. The study was approved by the Universiy of Stellenbosch.	
Selected for this study	We are doing research on women who suffered a stroke. We received your details from Rural Ability Foundation and community workers that come see you	
Aim of the study	This study aims to give an better understanding of how the area where Xhosa women who suffered a stroke live influences the nature of the activities they need to complete, to take part in the life roles in rural and urban environments.	
What this study entails	The study will be done in a rural part of the OR Tambo district in the Eastern Cape and the Khayelitsha district in the Western Cape.	
	You will be asked to complete a survey developed for this study and outcome measures used in stroke rehabilitation i.e. EQ-5D that looks at your quality of life and the Barthel Index which looks at the activities of daily living . You will also have an interview to about activities you may have problems with in your home and community. The discussion will be recorded.	
Your responsibility	Your responsibility in this study would be to answer all questions truthfully and to discuss your experiences in your home and community after suffering the stroke	
Benefit for taking part	You will not benefit immediately from takingpart in this study, but with your will help to make rehabilitation of other people with a stroke better in the future. You take part voluntary	
Risk involved	There are no risks involved in participating in this study	

Access to Medical information	Your information will be treated as private (confidential). Your records will be given a number in this study. Your name will not be written on any of the forms and none of your personal details will be visible. Only the study leader and research assistant will use the forms and information. These will not be shared with other people. All the information will be placed on a computer that will be password protected, that only the researcher will know. Your identity will not be used in any article or thesis written and you will remain unidentified. Information collected from medical records will be kept private.	
Cost involved with this study	You will not be paid to take part. There will be no cost for you to take part.	
Feedback	Feedback of the study results will be shared to the hospital and Rural Ability Foundation. The community worker will then come give you feedback on the the results of this study.	
Any Questions		
Eligibility Questions	How old are you? Have you had a stroke? When did you have the stroke? How long did you live in this area before the stroke? Do you have any communication problems that might limit your participation in this study? Did you have any problems before the stroke which limited your ability to participate in activities in your home or community?	
Semi-Structured Questionnaire		
D&E Questionnaire		
Barthel Index		
EQ-5D		
Check for Appropriate Referral		

Appendix 4 Demographic and Environmental Questionnaire

Demographic & Environment Questionnaire

<u>Patient Number</u>			<u>Project Ethics Number</u>			
1 How old are you?			years			
2 When did you have the stroke?			Months			
3 Do you have any other illness such as:	HPT	DM	Chol	RA	OA	Epilepsy
	Other:					
4 What are you getting medication for	HPT	DM	Chol	RA	OA	Epilepsy
	Other:					
5 Do you receive a grant?	Yes		No		Specify	
6 What is your marital status	Single	Married	Divorce	Living with Partner		
7 How many children do you have to look after?						
8 Do you have adults to look after?	Yes		No			
How many?						
9 How long have you been living in this home area?						
10 What type of house do you live in	Brick house		Flat		Informal dwelling	
	Other:					
11 Do you have electricity in your home?	Yes		No			
12 Where do you get water from	Tap inside house	tap outside house		community tap	River	Rain water tank
13 What fuel do you use to cook a meal?	Electricity	Gas	Parafin	wood	Solar panels	sun
	Generator					
14 Can you move around around your house?	Yes		No			
comment						
15 What is the surface like outside your house	Concreat, bricks, tar		Sand	Grass	Narrow pathways	Lose stones

What is the terrain like in your community?	Other								
		Concreat, bricks, tar	Sand	Grass	Narrow pathways	Lose stones			
	Other								
17 Can you move around in community?		Yes		No					
18 What transport did you use before the stroke?		Pushed	Own car	taxi	bus	Train	Bicycle	Private car	Dial-a ride
19 What transport do you use now?		Pushed	Own car	taxi	bus	Train	Bicycle	Private car	Dial-a ride
20 Can you access the transport?		Yes		No					
comments									
21 What assistive devices where you given?		crutches	Walking frame	Rollator	Wheelchair	Motorised wheelchair			
22 What assistive devices do you use?		crutches	Walking frame	Rollator	Wheelchair	Motorised wheelchair			
23 What assistive devices do you want to use?		crutches	Walking frame	Rollator	Wheelchair	Motorised wheelchair			
24 What type of toilet do you use?		Flush toilet	Long drop	Communal toilets	Bucket				
Other									
25 Where is the toilet located?		In the house	Outside next to the your home (within 10 meter)	More than 10 meters away from your home					
Other									
26 Can you get to the toilet?		Yes		No					
Comment									
27 What activities did you do in your home before the stroke?		Preparing meal	Cooking	Cleaning the house	Laundry	Gardening	Looking after dependants		
Other									
28 What activities can you now do in your home?		Preparing meal	Cooking	Cleaning the house	Laundry	Gardening	Looking after dependants		
Other									
29 What did you do or attend in the community before the stroke?		Work	Community events / gatherings	Religious	Shopping				
Other									

What do you do now in the
30 community?

Other

Work	Community events / gatherings	Religious	Shopping

31 Who looks after you

Adult family member	Home based care worker	Private person	Spouse	Child	Friends	Nobody
Other						

32 Do you pay them to look after you?

Yes		No	
-----	--	----	--

Which healthcare services do
33 you regularly attend

clinics		District Hospital		Academic Hospital		Traditional healer	
---------	--	----------------------	--	----------------------	--	-----------------------	--

Which healthcare practitioner do you
34 see?

Nurse	Home based carer	Doctor	Physiotherapist	Speech Therapist	Dietician
Psychologist	Social worker	Prosthetits	Radiographer	Occupational Therapist	
Other					

Appendix 5 The Barthel Index

THE BARTHEL INDEX

Patient Name: _____

Rater Name: _____

Date: _____

Activity	Score
FEEDING 0 = unable 5 = needs help cutting, spreading butter, etc., or requires modified diet 10 = independent	_____
BATHING 0 = dependent 5 = independent (or in shower)	_____
GROOMING 0 = needs to help with personal care 5 = independent face/hair/teeth/shaving (implements provided)	_____
DRESSING 0 = dependent 5 = needs help but can do about half unaided 10 = independent (including buttons, zips, laces, etc.)	_____
BOWELS 0 = incontinent (or needs to be given enemas) 5 = occasional accident 10 = continent	_____
BLADDER 0 = incontinent, or catheterized and unable to manage alone 5 = occasional accident 10 = continent	_____
TOILET USE 0 = dependent 5 = needs some help, but can do something alone 10 = independent (on and off, dressing, wiping)	_____
TRANSFERS (BED TO CHAIR AND BACK) 0 = unable, no sitting balance 5 = major help (one or two people, physical), can sit 10 = minor help (verbal or physical) 15 = independent	_____
MOBILITY (ON LEVEL SURFACES) 0 = immobile or < 50 yards 5 = wheelchair independent, including corners, > 50 yards 10 = walks with help of one person (verbal or physical) > 50 yards 15 = independent (but may use any aid; for example, stick) > 50 yards	_____
STAIRS 0 = unable 5 = needs help (verbal, physical, carrying aid) 10 = independent	_____

TOTAL (0–100): _____

Provided by the Internet Stroke Center — www.strokecenter.org

Appendix 6 EuroQol Five-Dimension Questionnaire (EQ-5D)



Iphepha lemibuzo ngezempilo

Inguqulelo yesiXhosa saseMzantsi Afrika

(Xhosa version for South Africa)

Beka uphawu kwibhokisi ibenye kwiqela ngalinye, elichaza imeko yempilo yakho NAMHLANJE, kwezi bhokisi zilandelayo.

UKUHAMBA

Andinazingxaki zokuhamba

☐

Ndineengxaki ezingephi zokuhamba

☐

Ndineengxaki eziphakathi zokuhamba

☐

Ndineengxaki eziqatseleyo zokuhamba

☐

Andikwazi kuhamba

☐

UKUZINONOPHELA ISIKU

Andinangxaki yokuzihlamba okanye ukuzinxibisa ngokwam

☐

Ndineengxaki ezingephi zokuzihlamba okanye ukuzinxibisa ngokwam

☐

Ndineengxaki eziphakathi zokuzihlamba okanye ukuzinxibisa ngokwam

☐

Ndineengxaki eziqatseleyo zokuzihlamba okanye zokuzinxibisa ngokwam

☐

Andikwazi ukuzihlamba okanye ukuzinxibisangokwam

☐

IMISETYENZANA YESIQHELO (*Umzk. umsebenzi, ukufunda, umsebenzi waphakathi kwekhaya, usapho okanye ezolonwabo*)

Andinangxaki nokuzenzela imisetyenzana yam yesiqhelo

☐

Ndineengxakana ezingephi zokuzenzela imisetyenzana yam yesiqhelo

☐

Ndineengxaki eziphakathi zokuzenzela imisetyenzana yam yesiqhelo

☐

Ndineengxaki eziqatseleyo zokuzenzela imisetyenzana yam yesiqhelo

☐

Andikwazi kuzenzela imisetyenzana yam yesiqhelo

☐

IINTLUNGU / UKUNGAZIVA KAKUHLE

Andinazintlungu okanye ukungaziva kakuhle

☐

Ndineentlungu ezingephi okanye ukungaziva kakuhle

☐

Ndineentlungu eziphakathi okanye ukungaziva kakuhle

☐

Ndineentlungu eziqatseleyo okanye ukungaziva kakuhle

☐

Ndineentlungu ezigqithileyo okanye ukungaziva kakuhle

☐

UKUXHALABA / UKUDAKUMBA

Andinaxhala okanye andidakumbanga

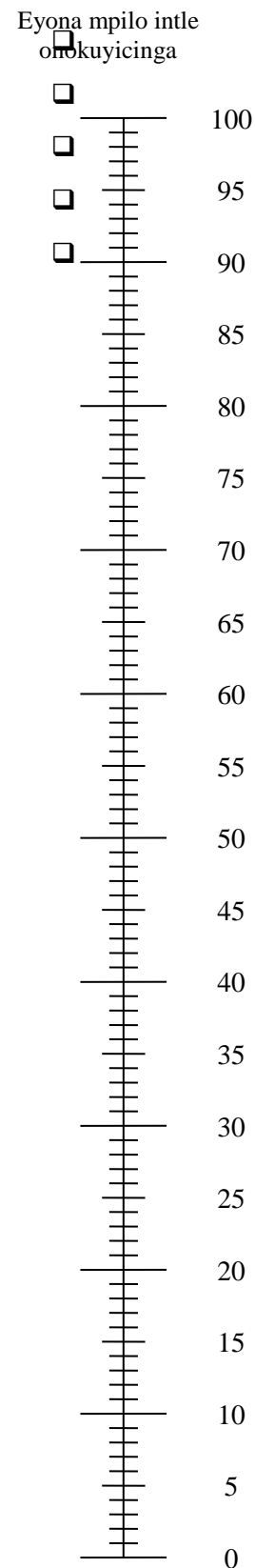
Ndibuxhalaba okanye ndinokudakumba okungephi

Ndinokuxhalaba ukuphakathi okanye ndidakumbile

Ndinokuxhalaba ngokuqatseleyo okanye ndidakumbile

Ndinokuxhalaba ngokugqithileyo okanye ndindakumbile

- Singathanda ukwazi ukuba impilo yakho intle okanye kangakanani NAMHLANJE.
- Esi sikali sinamanani asuka kwi-0 ukuya kwi-100.
- I-100 lithetha eyona meko intle yempilo unokuyicingela.
I-0 lithetha eyona meko imbi yempilo onokuyicingela.
- Phawula u-X kwisikali esibonisa ukuba impilo yakho intle okanye imbi kangakanani NAMHLANJE.
- Ngoku, nceda ubhale inani oliphawulileyo kwisikali kwibhokisi engezantsi.



IMPILO YAKHO NAMHLANJE =

Eyona mpilo imbi
onokuyicinga

Under each heading, please tick the ONE box that best describes your health TODAY.		The best health you can imagine	
MOBILITY I have no problems in walking about <input type="checkbox"/> I have slight problems in walking about <input type="checkbox"/> I have moderate problems in walking about <input type="checkbox"/> I have severe problems in walking about <input type="checkbox"/> I am unable to walk about <input type="checkbox"/>		1. We like to know how is your health today. 2. This scale is marked from 0 to 100. 3. 100 means the best health you can imagine. 0 means the worst health you can imagine.	
SELF-CARE I have no problems washing or dressing myself <input type="checkbox"/> I have slight problems washing or dressing myself <input type="checkbox"/> I have moderate problems washing or dressing myself <input type="checkbox"/> I have severe problems washing or dressing myself <input type="checkbox"/> I am unable to wash or dress myself <input type="checkbox"/>		4. Mark an X on the scale to indicate how is your health today. 5. Now, please note the number you marked on the scale in the box below.	
USUAL ACTIVITIES (e.g., work, study, housework, family or leisure activities) I have no problems doing my usual activities <input type="checkbox"/> I have slight problems doing my usual activities <input type="checkbox"/> I have moderate problems doing my usual activities <input type="checkbox"/> I have severe problems doing my usual activities <input type="checkbox"/> I am unable to do my usual activities <input type="checkbox"/>		Your Health Today = <input type="text"/>	
PAIN/DISCOMFORT I have no pain or discomfort <input type="checkbox"/> I have slight pain or discomfort <input type="checkbox"/> I have moderate pain or discomfort <input type="checkbox"/> I have severe pain or discomfort <input type="checkbox"/> I have extreme pain or discomfort <input type="checkbox"/>			
ANXIETY/DEPRESSION I am not anxious or depressed <input type="checkbox"/> I am slightly anxious or depressed <input type="checkbox"/> I am moderately anxious or depressed <input type="checkbox"/> I am very anxious or depressed <input type="checkbox"/> I am extremely anxious or depressed <input type="checkbox"/>			

Appendix 7 Semi- Structured Interview Guide

Participant Number		Tick	Comments
Leading Question: What are you struggling with now that you used to do before?			
	Tick	Comments	
-Identify Participation Restrictions responsibilities Self-care (bathing, washing, grooming, dressing)			
Mother / Carer (looking after children/other family members)			
Work / leisure activities (gardening, home maintenance, income generation)			
Religion / community meetings			
Other Responsibilities			
Cooking: what do you need to prepare meal and where do you do it			

Bathing: what do you need to do to wash yourself?		
Walking: where do you need to walk and how does terrain look		
Transfer: where do you sit or lie and how do you get into different positions		
Toilet: what do you use for toilet and where is it.		
Transport: what do you use to get around and where do you get it.		
How does your family and/or community assist you?		

Appendix 8 Qualitative Codebook

Addendum Codebook and quotations

Rural Codebook with definitions		
Nr	Codes	Definitions
1	Assistance	Participant needs assistance to complete activities and roles
2	Assistive Device	Devices that assist with the successful and independent completion of task
3	Barrier - Negative	Overarching theme for either participation roles, activities, body impairments or contextual factors that is seen by participants as a barrier and negative effect in their function
4	Bath Basin	task/activities/responsibilities associated with bathing in a washing basin
5	Bathing	Activity that relates to washing yourself
6	Bedmobility	Moving in the bed
7	Body Impairment / Pain	Body impairments expressed by participants that for example relates to pain, weakness, stiffness of a limb or body part
8	Boil Water	activity to boil water
9	Build House	activities and roles relating to building a new dwelling
10	Carry / Hold Object	task or activity related to carrying a object
11	Carry on Head	Carry object on participant head
12	Change Nappy	task/activity/responsibility to change nappy of children
13	Cleaning	Activity and roles to clean area where appropriate
14	Clinic Visit	task, activities or roles associated with going to healthcare services
15	Collect Wood / poles	To collect wood usually from forest that is only used for make structures in home environment for example roofs of dwellings or animal "kraals"
16	Community Court	A traditional event where community members can resolve issues with each other before the local chief
17	Community Meetings	Meetings held within each community with chief and elders to discuss and share important matters that arise
18	Community Support	Support offered, received or expected from participants community members
19	Cooking	Overarching theme that relates all roles and activities of cooking
20	cooking fuel	Fuel used for cooking
21	Cooking on the fire	Cooking on an open fire
22	Cultural Responsibilities	Self expressed responsibilities that relates to traditional roles of women in Xhosa culture
23	Dependence	Participant is fully dependant on other in activity or role
24	Dressing	the task or activity to dress either self or others
25	Electrical Appliance	Refers to any household appliance that needs electricity to function
26	Emotional Response	Participant expressed emotion connection topic

27	Exercises	Prescribed exercises given by therapist
28	Facilitator - Positive	Overarching theme for either participation roles, activities, body impairments or contextual factors that is seen by participants as a facilitator and positive effect in their function
29	Family Support	perception or reference to support received from family
30	Fear	any emotional reference to fear
31	Fear of Falling	any emotional reference to fear when doing an activity or task
32	Feeding	activity relates to participant feeding herself or being fed - placing food in mouth
33	Fence Maintenance	task or activity or role associated with repairing the fence
34	Finances / Income / Grant	Overarching theme that relates to all roles, responsibilities and activities involved with finances
35	Firewood Collect	To collect wood that is only used for fire.
36	Gardening	task, activities or roles associated with ploughing, maintaining, harvesting or other responsibilities associated with gardening
37	Grind Corn	Activity where corn is grinded in traditional manner to make maize
38	Grooming Hair	Relates to any activity that involves hair grooming for example brushing, washing, styling
39	Harvesting Food	Harvesting produce from garden that is used in home for cooking and feeding family members
40	Hire Assistance / Services	Hire assistance to help with the completion of task / activities in or around the home.
41	Hoeing	Act to prepare and maintain garden using a specific hoe tool
42	Home Maintenance	Activity or role that involves maintaining home or dwelling
43	Lack of Community Support	any emotional reference to fear
44	Lack of electricity	No access to electricity in dwelling
45	Lack of Family Support	reference to barrier experienced relating to perceived support from family members
46	Laundry	task, activity or roles associate with washing clothes, blankets etc
47	Looking After Children	Role of looking and caring for children
48	Looking after family members	Role of looking and caring for adult family members
49	Looking after Spouse	Role of looking and caring for spouse
50	Make Bricks	Traditional act of making bricks from a mixture of cow dung, soil and water
51	Make Fire	task/activity/responsibility to make a fire
52	Making Traditional Beer	The activities related to the preparations and brewing of traditional beer
53	Mobility Wheelchair	Participant mobilising with the use of a wheelchair either independent or with assistance of others.
54	parrafin	task/activities associated with acquisition of use of paraffin
55	Ploughing	Relates to preparation of garden or fields for sowing seeds. Can either be done with assistance of large animals as oxen or by hand
56	Preparing Food	Activities required to prepare food for cooking for example: peeling, rinsing, grinding or chopping food

57	Preparing grass for thatching	Act and role of cutting grass and preparing it in bunches to be used to thatch dwellings roof
58	Preperation for smearing surfaces	Activities needed to prepare the mixture used to smear walls and floors
59	Religion	task/activity/responsibility to partake in religious events/activities
60	River	natural source - any reference
61	Self Worth / Respect	Positive emotion, hope or expressed self worth in continuous participation in life roles or meaningful activities
62	Selfcare	Activities relating to looking after yourself
63	Shopping	task/activity/responsibilities for acquisition of goods through payments
64	Sitting on chair	to sit on a chair
65	Sitting on floor	Activity where participant sit on floor with legs straight and stretched out.
66	Sleeping "position"	Position in which the participant sleep in.
67	Smear Floors & Walls	Act of smearing the walls and floors of traditional hut with mixture of either cow dung soil for home maintenance or paint mixture decoration
68	Smear Myself	Participant smearing themselves with appropriate mixture relating to selfcare
69	Social gatherings	Relates to any activity where participant socialises with other members of the community
70	Social Group	Groups in community that has an overrating social or financial structure
71	Sourcing Food / Produce	Sourcing food to cook and feed the family.
72	Stomping corn	Act to stomp corn in traditional device to prepare for cooking. Different from grinding corn
73	Take Child to school / creche	task/activity/responsibility to take children to school
74	Taking Medication	task/activity/responsibility to take medication - take care of health
75	Taxi / Private Car	Use of taxi or private car as transportation
76	Terrain Mobility	relates to participants terrain over which they have to mobilise
77	Thatching Roof	Activity and roles that relates to thatching traditional dwellings roof
78	Toilet Long Drop Outside	The use of a long drop for toileting
79	Toileting	Overarching theme for activities involved in toileting
80	Toileting Bucket	The use of a bucket for toileting
81	Toileting Bushes	The use of a bushes for toileting
82	Traditional / Cultural Events	Events or social gathering that is described by the participant as a traditional event within their culture
83	traditional beer	Overarching theme that involves different activities required for the making and drinking of home brewed beer
84	Transfers	Moving from position or surface to the other example
85	Transport	Overarching theme for activities related to the use of transportation as means of mobility
86	Transport raining	Any activities or interactions related with private or public transportation specifically related to raining weather
87	upper limb function	relates to the participants ability or inability to use the upper limb in activities

88	Visit Neighbours	Activity to go to neighbours
89	Walking	task/activity associated with walking
90	Washing Dishes	Activity or task related to clean dishes by washing them
91	Water Collect	the activity related to collecting water from either communal tap, river, container
92	Work / Employment	role and activities to generate an income

Urban Codebook with definitions		
Column 1	Codes	Definitions
1	Adaptations	Relates to participant incorporating adaptations in activities to ensure successful execution
2	Assistance	Participant needs assistance to complete activities and roles
3	Assistive Device	Devices that assist with the successful and independent completion of task
4	Barriers - Negative	Overarching theme for either participation roles, activities, body impairments or contextual factors that is seen by participants as a barrier and negative effect in their function
5	Bath Basin	task/activities/responsibilities associated with bathing in a washing basin
6	Bath Water throw out	Traditional activity to throw bath water out of basin after participant wash themselves
7	Bathing	Activity that relates to washing yourself
8	Bed Mobility	Moving in the bed
9	Body Impairment / Pain	Impairments in body function expressed by participants that for example relates to pain, weakness, stiffness of a limb or body part
10	Boiling water	activity to boil water
11	Building a house	activities and roles relating to building a new dwelling
12	Bus	The use of bus as public transportation
13	Carry / Hold child	task and activities associated with carry a child
14	Carry object	Task or activity to carry an object
15	Carry on head	Carry object on participant head
16	Children School	task and activities required to get children to school either, walking with them or financial implications
17	Choir	task, activities and responsibilities associated with participating in choir
18	Cleaning	Activity and roles to clean area where appropriate
19	Clinic Visit	task, activities to go for visits to healthcare facilities
20	Community Meetings	Meetings held within each community with chief and elders to discuss and share important matters that arise
22	Community Support	Support offered, received or expected from participants' community members

23	Cooking on an open fire	Cooking on an open fire
24	Cooking	Overarching theme that relates all roles and activities of cooking
25	Cooking Fuel	Fuel used for cooking
26	Cultural / Traditional Responsibilities	Self-expressed responsibilities that relates to traditional roles of women in Xhosa culture
27	Dancing	task or activities associated with dancing
28	Debts	emotional responses or task or responsibilities associated with financial debt
29	Dependence	Participant is fully dependant on other in activity or role
30	Dressing	to dress yourself or others
31	Drinking Beer	to drink beer, social event or at home
32	Eastern Cape Responsibilities	Roles, activities and responsibilities that participants express to have in the Eastern Cape where family members or home is.
33	Electricity	any task, activities or responsibilities associated with acquiring or using electricity
34	Electrical Appliances	Refers to any household appliance that needs electricity to function
35	Emotional Response	Participant expressed emotion connection to topic - negative emotional connection due to loss of hope or inability to participate in meaningful activities
37	Exercises	Prescribed exercises given by therapist
38	Facilitator - Positive	Overarching theme for either participation roles, activities, body impairments or contextual factors that is seen by participants as a facilitator and positive effect in their function
39	Family Support	perception or reference to support received from family
40	Fear of falling / loosing balance	any emotional reference to fear
41	Fear of fire	any emotional reference to fear when doing an activity or task
42	feeding	activity relates to participant feeding herself or being fed - placing food in mouth
43	Finance / Income / Grant	Overarching theme that relates to all roles, responsibilities and activities involved with finances
44	Gardening	task, activities or roles associated with ploughing, maintaining, harvesting or other responsibilities associated with gardening
45	Grooming	activities/task/responsibility to groom yourself or others
46	Hanging up washing	to hang up washing - task/activity/responsibility
47	Hire Assistance / Services	Hire assistance to help with the completion of task / activities in or around the home.
48	Hoeing	Act to prepare and maintain garden using a specific hoe tool
49	Home Based Carers	any reference of home-based carer
50	Home Maintenance	Activity or role that involves maintaining home or dwelling
51	Ironing	task / activity to iron
52	Lack of Assistive Devices	lack of assistive devices to assist with function

53	Lack of community support	perception of lack of community assistance
54	Lack of Electricity	No access to electricity in dwelling
55	Lack of Family Support	reference to poor family support
56	Laundry	Washing of clothes or blankets
57	Looking After Children	Role of looking and caring for children
58	Looking after Family members	Role of looking and caring for adult family members
59	Looking after Spouse	Role of looking and caring for spouse
60	Make Bricks	Traditional act of making bricks from a mixture of cow dung, soil and water
61	Making Beds	Activity to neatly covering bed with either blankets, sheets , duvets and pillows
62	Mobility Wheelchair	Participant mobilising with the use of a wheelchair either independent or with assistance of others.
63	No Garden	reference to not having a garden at home or in community
64	Paraffin	reference to cooking fuel - any task or activities associated with it
65	Ploughing	Relates to preparation of garden or fields for sowing seeds. Can either be done with assistance of large animals as oxen or by hand
66	Preparing Food	Activities required to prepare food for cooking for example: peeling, rinsing, grinding or chopping food
67	Rain	reference to rainy weather
68	Religion	task/activity/responsibility to partake in religious events/activities
69	Self-worth / Respect	Positive emotion, hope or expressed self-worth in continuous participation in life roles or meaningful activities
70	Selfcare	Overarching theme for activities relating to participants looking after personal appearance
71	Shopping	task/activity/responsibilities for acquisition of goods through payments
72	Sitting on Chair	to sit in chair
73	Sitting on floor	Activity where participant sit on floor with legs straight and stretched out.
74	Sitting Position	Position in which the participant sleep in.
75	Smear myself	Participant smearing themselves with appropriate mixture relating to selfcare
76	Smear Walls and Floors	Act of smearing the walls and floors of traditional hut with mixture of either cow dung soil for home maintenance or paint mixture decoration
77	Social Gathering	Relates to any activity where participant socialises with other members of the community
78	Social Groups	Groups in community that has an overarching social or financial structure
79	Sourching Food / Produce	Souring food to cook and feed the family.
80	Speaking / Communication	overarching theme for all activities that relates to communication by means of speaking and vocalisation

81	Street Meetings	Meetings held within each residential area or street to discuss and share important matters that arise
82	Taking children to school / Care Centre	task/activity/responsibility to take children to school
83	Taxi	Use of taxi as transportation
84	Teaching children chores	to teach children chores at home - authority
85	Terrain Mobility	relates to participants terrain over which they have to mobilise
86	Tie Doek	Act of tying traditional head scarf over the women's head
87	Toilet	Overarching theme for activities involved in toileting
88	Toilet Communal	The use of communal toilets
89	Toilet flush Inside	The use of inside flush toilets
90	Toilet Flush Outside	The use of outside flush toilets
91	Toilet informal / Bushes	The use of bushes informal toilets
92	Transfers	Transfer from one position to the other
93	Transport	Overarching theme for activities related to the use of transportation as means of mobility
94	Upper limb function	relates to the participants' ability or inability to use the upper limb in activities
95	Vote	The activity to vote in government or local elections
96	Walking	to vote in elections
97	Washing Dishes	task/activity/responsibility associated with washing dishes
98	Water Collect	the activity related to collecting water from either communal tap, river, container
99	Water Tap communal	Access to water from communal tap
100	Water Tap inside house	Access to water from tap inside the dwelling
101	Work / Employment	role and activities to generate an income

Examples of coding of transcriptions			
Primary Doc	Text Line	Codes	Quotation
P5	141	Cultural Responsibilities, Facilitator - Positive, Family Support, Social gatherings, Transport	Interviewer: How would they know that you want to go somewhere? Participant 5: Sometimes the problem is there by them. As you know, I am a daughter at my father's family and they have to include me, even if I am like this now. Even if I am this scrap I am still a daughter and they must come and fetch me.
P6	18	Barrier - Negative, Gardening, Hoeing, upper limb function	Interviewer: Why are you unable to hoe? Participant 6: To hoe you need both hands to hold the hoe. So I only have one hand. Even if I try to use the other one it can't hold on, that the reason.
P15	129	Barriers - Negative, Finance / Income / Grant, Hire Assistance / Services, Mobility Wheelchair, Shopping, Transport	I don't normally go to the shops; I only go on the 1st when I have to receive my grant there at the mall. I will go there. It's even difficult with the wheelchair as it is always full of the people. It's a bit far so we use to hire car to get there. It will wait for me while I am getting my pay (grant).
P6	83	Feeding, Shopping, Sourcing Food / Produce	Participant 6: I feed them with my grant money, there is no other way.
P20	19	Barriers - Negative, Dressing, Fear of falling / loosing balance	And then the clothes. I can't go to the wardrobe to take my things, because I am afraid to fall you see. I can't. I can't take my things down there. If I did you see what I am doing I am just turning to the wardrobe and then I take my tracksuit I take it like this
P21	69	Barriers - Negative, Religion, Terrain Mobility, Transport, Walking	Participant 21: It's all those that I have already mentioned. Those things to assisting where there is something. Like now there is even a church in faraway places like in Nyanga. I can't get to Nyanga as I take a bus and it is a distance between the house and the bus stop. Those are the things I am unable to do now.

Appendix 9: EQ-5D Health State Dimensions Pivot Table

Setting	No Problem	Slight Problem	Moderate Problem	Severe Problem	Extreme Problem
Mobility					
Rural (n=11)	18,2% (n=2)	18,2% (n= 2)	27,3% (n=3)	27,3% (n=3)	9,1%(n=1)
Urban (n=9)	22,2% (n=2)	11,1% (n=1)	22,2% (n=2)	33,3% (n=3)	11,1% (n=1)
Self-care					
Rural (n=11)	54,5% (n=6)	18,2% (n=2)	9,1% (n=1)	18,2% (n=2)	0,0% (n=0)
Urban (n=9)	33,3% (n=3)	0,0% (n=0)	22,2% (n=2)	33,3% (n=3)	11,1% (n=1)
Usual Activities					
Rural (n=11)	18,2% (n=2)	9,1% (n=1)	18,2% (n=2)	18,2% (n=2)	36,4% (n=4)
Urban (n=9)	0,0% (n=0)	22,2% (n=2)	22,2% (n=2)	33,3% (n=3)	22,2% (n=2)
Pain					
Rural (n=11)	27,3% (n=3)	9,1% (n=1)	36,4% (n=4)	27,3% (n=3)	0,0% (n=0)
Urban (n=9)	22,2% (n=2)	22,2% (n=2)	22,2% (n=2)	11,1% (n=1)	22,2% (n=2)
Anxiety and Depression					
Rural (n=11)	18,2% (n=2)	45,5% (n=6)	9,1% (n=1)	9,1% (n=1)	18,2% (n=2)
Urban (n=9)	22,2% (n=2)	22,2% (n=2)	33,3% (n=3)	11,1% (n=1)	11,1% (n=1)

